

Cancer Journey Portfolio

Navigation: A Guide to Implementing Best Practices in Person-Centred Care

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Background

Navigation in cancer care can be defined as “a proactive, intentional process of collaborating with a person and his or her family to provide guidance as they negotiate the maze of treatments, services and potential barriers throughout the cancer journey” (Cancer Journey Action Group, 2010). Many provinces in Canada now recognize that Navigation is a key component of an integrated system of cancer care and an effective way to improve the delivery of person-centred care. There is growing interest in Navigation programs among patients, health care providers and policy-makers across Canada as a means to improve coordination and continuity of care, and to facilitate timely access to health care services. Navigation initiatives have been implemented in all provinces and one territory, and services continue to expand.

The Supportive Care Framework, which provides a full conceptualization of patient needs and the help required from health care providers to address the needs of all cancer patients, is foundational to the development of Navigation in Canada (Fitch, 1994; Fitch, 2008). The framework reflects a person-centred approach to patient care and has been used to inform program and policy planning (Fitch, 2008; Howell and Sussman, 2008).

From 2008 to 2012, the Cancer Journey Portfolio¹ (Cancer Journey) of the Canadian Partnership Against Cancer (the Partnership) has led the Strategic Initiative Toward Integrated Person-Centred Cancer Care. The initiative aims to enhance delivery of cancer care services by supporting innovative practices in Navigation, Screening for Distress and Survivorship. Cancer Journey has supported various national activities regarding Navigation to enhance development of reliable evidence, best practices and national collaboration and thus advance the field of Navigation in cancer care. This guide is intended to capture the key learnings from these activities in implementation, evaluation, resource development and national collaboration, and to share recent advances in knowledge and resource production.

Conceptualizing Navigation

Cancer Journey advocates a broad conceptualization of Navigation, with different modalities, all of which improve care delivery and accessibility. Modes of Navigation may include:

- **Professional Navigation.** The navigator is a health care professional with oncology expertise and experience.
- **Peer or Lay Navigation.** Peer navigators usually have had a cancer experience as a survivor or caregiver, while lay navigators may not have had direct experience

¹ The Cancer Journey portfolio of the Canadian Partnership Against Cancer has had several name changes. It began in 2008 as “Rebalance Focus” and then was known as “Cancer Journey” from 2009 to March 2012. In April 2012 it became the “Person-Centred Perspective” portfolio.

with cancer. Peer and lay navigators are trained and generally work as volunteers, though they can be paid.

- **Online (self or virtual) Navigation.** An individual and/or family members take it upon themselves to find the information and services they need, often within the emerging arena of virtual Navigation tools and online resources.
- **System-based Navigation.** The goal is to redesign cancer care procedures and pathways to decrease delays and increase efficiency.

Self-navigation might be sufficient to meet the needs of some people with cancer and their families, while others might use online aids as a complement to assisted forms of Navigation (professional or peer/lay). Navigators may employ virtual tools and resources in addition to one-on-one consultation. Some individuals and families may find that different models of Navigation are best suited to their needs at different stages of the cancer experience. Navigation can occur at any point in the trajectory of the patient journey, although at present most programs in Canada concentrate on the treatment phase, with some focusing on the diagnostic phase (Cancer Journey Portfolio, 2011).

Some Navigation programs are explicitly and solely focused on population-based improvements. Many programs focus on facilitating continuity of care between primary care and oncology. Many are also concerned with identifying and overcoming systemic challenges. Overall, it is important to note that there is no single, best method of Navigation; rather, it is crucial that people living with cancer are aware of the various forms and options available to them, while improvements in quality and continuity of care remain key priorities at both the individual and system levels.

In this broad conceptualization, Navigation is a system of services and resources that are mobilized based on the immediacy and severity of patients' needs. Ideally, this system would include a function that accurately targets the right service at the right time for the right patient, with great efficiency and little duplication of effort. This broad conceptualization maintains the system as the focus for improvement, and holds patients at the centre, to ensure that each patient's experience of care is optimal. With this approach, Navigation has impact well beyond cancer care, with benefits for the larger health care system.

Developments in Navigation, 2008-2012

The field of Navigation in health care is in an exciting stage of development. There are many similarities and synergies in Navigation initiatives across the country, and multiple opportunities for national collaboration. As Cancer Journey's first mandate comes to a close, it is clear that Navigation in cancer care is recognized as a key element of improving and enhancing the delivery of cancer care in Canada. The goals of improved, person-centred care and greater system efficiency are driving initiatives in Navigation. Patients need to expect effective Navigation and all providers need to

take responsibility for Navigation. Further, mechanisms need to be put in place to monitor and improve system performance.

Much has been accomplished in the last five years in the field of Navigation. In 2007, there were two permanent programs in professional Navigation, one in Nova Scotia and one in Quebec. In a survey of Navigation activity conducted by Cancer Journey in November 2011, there were professional navigators in every province and in one territory, four provinces also had volunteer navigators (see Figure 1) and eight provinces had a coordinated Navigation strategy.

Figure 1: Navigation Activity in Canada, 2007 and 2011



In the last five years, Cancer Journey has been involved in numerous activities to advance the field of Navigation across the country. The focus has been on establishing some consensus about the concept of Navigation and the parameters of the different modalities of Navigation. The activities have focussed on the following key areas, and are tabled in detail below (see Table 1):

- **Workshops:** National workshops brought together key stakeholders to create consensus on the concept and functions of different forms of Navigation, and to share emerging best practices and key learnings. National, provincial and regional workshops provided a forum for the Cancer Journey Navigation Team to provide leadership in planning and implementing professional and peer/lay Navigation.
- **Implementation:** The team monitored and evaluated the implementation of professional and peer/lay navigators in four jurisdictions to learn about the implementation process.
- **Navigation Knowledge, Tools and Resources:** Through national collaborative efforts, experts in the field of Navigation have worked extensively to create useful tools and resources based on the best available evidence.

Table 1: Cancer Journey Navigation Activities

| National Workshops |
|--|
| <p><i>Cancer Patient Navigation National Workshops</i></p> <p><i>Winnipeg • December 7, 2007</i> <i>Fredericton • January 18, 2008</i> <i>Edmonton • February 12, 2008</i></p> <p>To build a collaborative Canadian approach to planning an accelerated adaptation of Navigation systems for cancer patients, survivors and families.</p> |
| Professional and Peer/Lay Volunteer Navigation Workshops |
| <p><i>Peer/Lay Volunteer • November 7, 2008 • Toronto</i> <i>Professional • December 8, 2008 • Toronto</i></p> <p>Peer/Lay Volunteer: To explore the concept of Peer/Lay Volunteer Navigation and to reach a consensus on its elements and next steps to develop the field.</p> <p>Professional: To gather information about professional Navigation programs and activities across the country, and to begin to delineate how Cancer Journey can collaborate with jurisdictions to advance the agenda of professional Navigation in cancer care.</p> |
| Navigation Grid Development Workshops |
| <p><i>July 24, 2009 • Toronto, Ontario</i> <i>November 26, 2009 • Montreal, Quebec</i></p> <p>Meeting #1: To draft a framework (the Navigation Grid) with a national working group. The Grid is intended to provide general definitions of and distinctions between the two models of navigation – professional and peer/lay volunteer – and to work as a guide for new programs.</p> <p>Meeting #2: To discuss, revise and refine the Navigation Grid based on the working group's feedback.</p> |
| National Navigation Workshop |
| <p><i>November 22-23, 2011 • Ottawa, Ontario</i></p> <p>A national meeting to assess progress in the field of Navigation from 2008 to 2011, and to identify priorities and next steps for action at local, provincial and national levels.</p> |

Provincial and Regional Workshops

British Columbia Cancer Agency (BCCA) Think Navigation Tank

July 11, 2009 • Prince George, British Columbia

To clarify the concept of Navigation and to learn about professional and volunteer models of Navigation to develop Navigation programs in British Columbia.

Atlantic Consortium Workshop

September 29–October 1, 2011 • Halifax, Nova Scotia

To facilitate interprovincial networking, education and knowledge exchange among Navigation professionals in the four Atlantic provinces that were implementing or continuing Navigation programs.

Rural Manitoba Cancer Patient Navigation Workshop

June 1, 2011 • Winnipeg, Manitoba

To learn about Cancer Journey's national Navigation initiative and CancerCare Manitoba's system-based analysis of patient Navigation. To engage participants in identifying benefits, challenges and next steps to regional implementation of rural cancer patient Navigation.

Newfoundland Navigation Workshop

March 23, 2012 • St. John's, Newfoundland

To discuss progress in Newfoundland's professional Navigation program, which began in April 2011 to consult with national and regional experts in professional Navigation.

Navigation Implementation

Cancer Journey partnered with the following jurisdictions to implement and evaluate volunteer and professional Navigation:

- **British Columbia Cancer Agency (May 2009 - August 2010):** To develop and evaluate a Peer Navigation Training Toolkit for Chinese-speaking patients with cancer.
- **British Columbia Cancer Agency (June 2010 - November 2011):** To develop and evaluate a volunteer Navigation training program and intervention for newly diagnosed colorectal and lung cancer patients.
- **CancerCare Manitoba (2011 - 2012):** To implement rural Navigation in community cancer programs in three regions.
- **Cancer Care Ontario (April 2010 - January 2012):** To support evaluation of the role of navigators for colorectal and thoracic cancer patients in the Diagnostic Assessment Program in 14 cancer centres.

Navigation Knowledge, Tools and Resources

The Navigation Project (2007-2012)

To produce improved knowledge and tools in the field of professional Navigation, Cancer Journey collaborated with a team of national experts to:

- develop a Professional Navigation Conceptual Framework;
- adapt and validate three relevant research outcomes identified with the Professional Navigation Conceptual Framework: Distress (PSSCAN); Empowerment (HeiQ); and Unmet Needs (SUNS/SPUNS) in French;
- develop clinical needs assessment tools and a training manual for professional navigators;
- evaluate the implementation process for Navigation (Fillion, Aubin, de Serres et al., 2010);
- evaluate implementation of Screening for Distress with navigators (Fillion, Cook, Veillette et al., 2011);
- adapt and validate the content of the manuals of the Cancer Transition program (participants and facilitators) in French;
- adapt and validate the content of the manual and the DVD of the NUCARE program in French;
- pilot Cancer Transitions and online support groups in French.

Virtual Navigation Pilot (May 2009-February 2010)

This pilot evaluated the introduction of the Oncology Interactive Navigator™ (OIN) tool in seven cancer centres across Canada. Findings from this study are meant to help partner organizations (i.e., provincial cancer agencies and cancer centres) assess the applicability and appropriateness of introducing the OIN as a virtual navigation tool in routine cancer care.

Guides to Implementing Navigation

Cancer Journey produced a guide to assist jurisdictions with implementing and evaluating peer/lay and professional Navigation:

- [Guide to Implementing Navigation](#), 2010 (in English and French)
This guide discusses the emergence of the role of cancer patient navigators and reviews the literature to date on professional and peer/lay Navigation. It also contains a chapter on implementation, with examples of tools to implement a professional program.

The purpose of this guide is to convey the advances made in the field of Navigation as a result of the above activities and to highlight key learnings and approaches from the evaluation of Navigation programs that were commissioned by Cancer Journey. Chapters 1 through 3 present recent advances in the development of professional, volunteer and virtual Navigation. Chapter 4 discusses the topic of change management to address some useful strategies, tools and approaches to managing and achieving practice change when implementing Navigation programs. One of the key findings from Cancer Journey's national evaluation is that a change management approach is beneficial to implementing a new role or new practice in a health care environment (Consultation Nicolas Inc., 2012; PICEPS Consulting Inc., 2012). Chapter 5 focuses on implementation and presents key findings from the external evaluation of three Navigation programs across Canada. Chapter 6 provides some tools and methods to improve quality and to evaluate Navigation programs. And Chapter 7 provides orientation to relevant resources available for Navigation.

Chapter 1: Professional Navigation

This chapter describes recent developments in the field of professional Navigation and presents several models, a conceptual framework and competencies. The chapter also considers the topic of education and training.

Professional Navigation across Canada

Across the country, professional Navigation programs have been designed to address the specific needs and gaps of various target populations, so program parameters vary. A survey of Navigation activity across Canada established that most programs focus on newly diagnosed adult patients, where the population is defined by tumour site (Cancer Journey Portfolio, 2011). In New Brunswick, the program focusses on pediatric patients. Numerous programs target high-needs patients or aim to address gaps in accessibility and care for patients in rural and remote communities. It appears that most programs span the trajectory from diagnosis through treatment to survivorship, but some programs target the diagnostic phase. In Ontario, a patient Navigation program has been developed for Aboriginal cancer patients, and several other provinces are exploring the development of similar programs (Cancer Journey Portfolio, 2011). The majority of professional roles are assumed by oncology nurses, but in some programs professional navigators are social workers. A combined model also exists, in which social workers work with oncology nurses in a team approach. There is also the recognition that clerical or administrative support is required to assist navigators when workloads increase.

Recent Research in Professional Navigation

The British Columbia Patient Navigation Model (BCPNM) focuses on addressing gaps and transitions in care across the cancer trajectory. In this model, the navigator role consists of six integral components (Doll, Stephen, Barroetavena et al., 2005; Pedersen and Hack, 2011):

- providing information,
- providing emotional support,
- facilitating decision-making,
- linking to resources,
- providing practical assistance,
- identifying and developing community supports.

The model has been evaluated and found suitable as a practice model that can be adapted to numerous contexts (Pedersen and Hack, 2011).

The first professional Navigation programs in Canada emerged in Nova Scotia in 2001 and in Quebec in 2007. The “*infirmière pivot en oncologie*” (Pivot Nurses in Oncology [PNOs]) in Quebec and Cancer Patient Navigators (CPNs) in Nova Scotia have become well-established and well-utilized services that span the hospital and community sectors. The programs have evolved into models of Navigation that are characterized by oncology nurse specialization and care management. In Quebec, professional navigators are based in cancer clinics, and the role “corresponds to a more comprehensive medical or social model of case management that values humanization of the care trajectory and empowerment of the patient and family; a model based on a patient-centered philosophy of care” (Fillion, Cook, Veillette et al., 2012).

Navigators in both programs assist newly diagnosed cancer patients and their families, and continue to offer support throughout the care trajectory. The navigators in both programs have similar roles and functions, with the main distinction being that Quebec’s PNOs are primarily based in hospitals, while Nova Scotia’s CPNs are primarily based in the community (Fillion, Cook, Veillette et al., 2011).

Scope of the Role

The navigator role was created to ensure that all non-medical or supportive care needs are assessed and addressed throughout the cancer journey. The goal is to ensure that patients experience less distress and are able to more fully engage in managing their care. In identifying needs and connecting patients to the most appropriate resources, navigators help address potential gaps and enhance continuity of care.

Professional patient navigators provide care directly to patients, providing such critical functions as assessment, implementation and evaluation of clinical and supportive care needs throughout the cancer journey. To fulfill these functions, navigators must draw on a range of clinical, mental and psychosocial competencies. They must have extensive cancer knowledge. Navigators must also be able to facilitate a coordinated approach, provide emotional and psychological support, engage in caring and therapeutic communication and relationships, and enable education and information sharing. Navigators also need skills in critical thinking and analysis, team building and collaboration, and must be able to identify and solve problems.

Professional navigators must be able to:

- identify patients' health and supportive care needs, and help patients and anticipate and overcome barriers;
- learn about patients' prognoses and consider their knowledge about their disease;
- establish a therapeutic relationship, build trust and confidence, and enhance patients' problem-solving abilities;
- identify the significant features of patients' physical and social environments, and the range of available services;
- use a systematic, culturally appropriate assessment approach that is sensitive to language differences;
- support patients in making informed decisions by providing access to and facilitating understanding of information;
- identify and accommodate different literacy levels and learning abilities;
- coordinate the range of resources available to patients and families, including advocacy, education and prevention.

The Professional Navigation Framework

Several teams of researchers in Quebec and Nova Scotia developed a Professional Navigation Framework (Fillion et al., 2012). The researchers matched competencies to the roles based on Canadian oncology nursing practice standards and competencies (Cook, Fillion, Fitch et al., forthcoming). Another team investigated the variation and frequency of nursing interventions based on the framework's four roles (Skrutkowski, Saucier, Ritchie et al., 2011).

The Professional Navigation Conceptual Framework (see Appendix H) accounts for the two dimensions of professional Navigation. The first dimension is health-system-oriented and refers to the continuity of care. The second is person-centred and corresponds to patient empowerment. Continuity of care includes three concepts: information, management and relational continuity. Patient and family empowerment is also divided into three concepts based on self-management principles: active coping, can-

cer self-management and supportive care. For each of the six concepts, clinical processes/functions and outcomes are defined. The framework was validated by Navigation health care professionals in Quebec and Nova Scotia (Fillion et al., 2012).

Researchers have begun to investigate the activities and interventions conducted by pivot nurses in oncology (PNOs) in Quebec to better understand the nature of Navigation. The interventions of 12 PNOs were documented over a period of three years according to a standardized taxonomy of nine nursing intervention categories and one administrative/clerical category (Skrutkowski et al., 2011). The data were organized according to the four roles of the PNO to show that “by the third year, coordination of care comprised 38.4% of interventions, while assessment comprised 32.4%, support 19.6% and teaching/information 9.6%” (Skrutkowski et al., 2011, p. 221). The researchers conclude that the Quebec model is within the scope of practice of specialized oncology nurses.

Using the Framework

The Professional Navigation Conceptual Framework can be adapted and is useful in many ways. It can assist with clarifying the navigator’s role and delineating the scope of practice. It can help to identify the resource and education needs of navigators. It can also assist with evaluation because it lists relevant outcomes with examples of validated tools that can be used to assess these outcomes.

Professional Competencies

The Professional Navigation Conceptual Framework has been mapped against Canadian oncology nursing practice standards and competencies (Cook et al., forthcoming). See Appendix I for the Core Competencies Framework, which takes the six concepts of the professional framework and delineates key functions, domains of practice and core competencies. Through the mapping exercise, the practice domains and competencies were condensed into three core domains of practice:

- Providing information and education
- Providing emotional and supportive care
- Facilitating continuity of care and coordination of services within the context of an interdisciplinary team approach

The development of this framework highlights the education and training requirements for professional navigators. The following section outlines the three core domains in more detail.

Core Areas of Practice

Providing Information and Education

Cancer patients often need to absorb information while they are experiencing high levels of anxiety, uncertainty and emotional stress, yet this is often the time when they receive the most information (Echlin and Rees, 2002). In this state, information-processing abilities are compromised and most patients retain very little. Navigators must be able to develop effective strategies to ensure that critical information is effectively learned, and repeat and reinforce any critical information that may have been missed. Helping patients understand and be actively engaged in their treatment plan and other aspects of care is an important part of the navigator role.

This domain incorporates competencies that reflect the ability of professional navigators to provide comprehensive, specialized and individualized information to clients about the pathophysiology of cancer and its effects, treatment approaches, supportive care and self-management strategies. Navigators need to provide such information using evidence-based educational strategies that are consistent with individual clinical circumstances, preferences, information and self-care needs. This domain includes the ability to explain or reinforce information that is being discussed or handed to patients by other health care providers and to help patients and families or caregivers understand treatment plans and other aspects of care. These competencies are intended to impart knowledge and skills for self-care, decision-making and compliance.

In this domain, professional navigators:

- use evidence-based information to help patients and families make informed decisions;
- facilitate the exchange of information and care planning among the members of interprofessional health care teams, including patients and families;
- educate and support patients in self-care strategies;
- provide patient education in a concise and efficient manner, tailored to each patient's needs and learning style;
- provide information to patients and families to facilitate decision-making, adherence to cancer treatment, supportive care and follow-up;
- maintain updated information about side-effect management, nutrition, emotional coping and other skills, and communicate this information to others;
- incorporate patients' developmental learning needs, cultural values and preferences in planning patient and family teaching;
- use appropriate mechanisms to locate and access current and relevant information about the patient and family, and the disease or care plan.

Providing Emotional and Supportive Care

This domain comprises competency standards that reflect the ability of navigators to identify multiple physical, psychological, social, sexual and spiritual needs of clients throughout the continuum of cancer care. It is also about navigators' abilities to implement evidence-based supportive care interventions in a flexible and responsive manner in the context of a collaborative interdisciplinary approach to care. The ability to identify sources of distress and to help patients manage and cope with such distress is a critical dimension of the navigator role. To provide emotional and supportive care requires exploration of fears and anxieties about disease progression, mortality, dying, body image or sexual health. Screening for Distress is a method of rapidly identifying patients with psychosocial distress. For more information about the implementation of Screening for Distress, refer to *Integrating Screening for Distress, The 6th Vital Sign* in Chapter 5.

Competencies in this area demonstrate the personal, collaborative and therapeutic approach, which enhances the effectiveness navigators. These competencies speak to the critical importance of interpersonal transactions.

In this domain, professional navigators:

- establish therapeutic relationships with patients, families and other caregivers to facilitate coping with sensitive issues;
- facilitate patient and family decision-making regarding complex treatment, symptom management and end-of-life care;
- assess sources of psychosocial and spiritual distress and plan appropriate management;
- engage in therapeutic conversations, exploring fears and anxieties about disease, treatment, side-effects and outcomes;
- refer patients and families to appropriate support services;
- perform comprehensive and timely assessment to identify current and potential needs and concerns;
- foster coping skills using existing supports and resources to maintain or improve each patient's quality of life;
- facilitate and support each patient's ability to make decisions, solve problems, and set and prioritize goals;
- collaborate with the interdisciplinary team to optimize health outcomes and access services and resources.

Facilitating Continuity of Care and Coordination of Services

Continuity of care has been defined as the delivery of services by different providers in a coherent, logical and timely fashion consistent with each patient's medical needs and personal context. How complex care is coordinated can affect a patient's chance of receiving the full complement of care provided by multiple providers. Studies have shown that better coordination of outpatient care is associated with higher levels of perceived health status and better access to preventive services. The navigator role is designed to assist patients in making their way through the complex maze of the cancer care system.

This domain comprises navigator competencies to facilitate a collaborative and coordinated approach to care planning, implementation and evaluation by helping patients, their families and their health care teams work together effectively. Navigators ensure that the appropriate information flows between team members and that a comprehensive range of health and support services are delivered in a timely fashion by providing a link between patients, their health care team, the hospital and community services at various stages of the cancer journey. This domain is particularly important in rural settings. These competencies help improve health outcomes for patients, communities and systems by promoting the delivery of clinical services within an integrated system of health care.

Within this domain, professional navigators:

- facilitate coordination of patient-centred care throughout the cancer continuum;
- provide patients and families a consistent and therapeutic relationship throughout the cancer continuum;
- facilitate transitions between health care settings to provide continuity of care;
- use referral pathways and assessments to link patients to the right health professionals, resources and support systems in a timely manner;
- initiate, advocate and mobilize agency and community resources needed by patients and families at different points of time and in different care settings;
- facilitate the exchange of information across the continuum of care, health care settings and providers;
- use communication and collaborative skills to support each patient's preferred role in negotiating their care and advocate for their decisions and preferences with the interprofessional care team;
- identify aspects of the health care system that create barriers to comprehensive cancer care and long-term care for cancer survivors;
- incorporate knowledge of payment and reimbursement systems and financial resources into the plan of care;

- coordinate care with attention to resource availability, accessibility, quality and cost-effectiveness;
- coordinate care within a context of functional status, cultural considerations, spiritual needs, family or caregiver needs, and ethical principles;
- build collaborative, interdisciplinary relationships to provide optimal care to patients with cancer.

In addition to dedicated training for professional navigators, ongoing education and support are necessary to meet the demands of the role. Many regions across the country are beginning to build communities of practice for this purpose. These communities may use online resources to link Navigation professionals and to provide professional development and support.

Resources to Support the Development of Core Competencies

- Alberta Health Services Cancer Patient Navigation Course for Professionals (cost associated): <http://ACB.ondec@albertahealthservices.ca>
 - deSouza Institute Patient Navigation Course (free to nurses in cancer care in Ontario): <http://desouzanurse.ca/courses/patient-navigation-05-credits>
 - Interprofessional Online Distance Education (IPODE) Screening for Distress Education Program (free): <http://www.ipode.ca/>
 - Cross Cancer Institute, ONDEC - Oncology Nursing Distance Education Course: <http://www.albertahealthservices.ca/2301.asp>
 - American Psychosocial Oncology Society (APOS), Online Education: <http://www.apos-society.org/professionals/meetings-ed/webcasts.aspx>
 - Canadian Association of Nurses in Oncology (CANO): <http://www.cano-acio.org/>
 - Bastable, SB. (2006). *Essentials of Patient Education*. Sudbury, MA: Jones and Bartlett Publishers.
 - CPEN (Cancer Patient Education Network): <http://www.cancerpatienteducation.org/>
 - Cancer Journey Portfolio *Guide to Implementing Screening for Distress, The 6th Vital Sign: Best Practices in Person-Centred Care*, 2012
 - Guidelines for Psychosocial Assessment of Adult Cancer Patients, and Pan-Canadian Symptom Management Guidelines: www.capo.ca
 - Pan-Canadian Clinical Practice Guideline Protocols for Telephone/Internet Support (in [English](#) and [French](#))
 - International Psycho-Oncology Society – IPOSE: http://www.ipos-society.org/education/core_curriculum/core_curriculum.aspx
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Implementation and Use of Competencies

Navigation programs require different competencies depending on the specific scope of the role, the setting, the duration of program delivery and overall differences in program goals as well as regional needs and resources. For example, Quebec's PNOs play a significant role in symptom management and care and therefore require high level competencies in clinical care. Nova Scotia's CPNs focus on education and preparing information for patients as well as coordination of care between the cancer centres and the community.

Ultimately the outcomes that can be achieved are:

- A therapeutic relationship between a patient and at least one provider, who develops accumulated knowledge of the patient as a person.
- A consistent and coherent approach to the management of cancer that is responsive to a patient's changing needs.
- Services that complement each other so that required services are not missed, duplicated or poorly timed.

Conclusion

Identifying Navigation competencies provides a framework to develop new Navigation programs, develop and update job descriptions, support and understand the navigator role, and facilitate program and job evaluations. Additionally, competencies can be used to determine educational requirements to facilitate development and advancement of the skills, knowledge and values necessary for the practice of professional Navigation.

By being comprehensive, the Professional Navigation Conceptual Framework can be adapted according to the needs of any organization. The first step is to understand the challenge that needs to be resolved, thus the framework can help guide managers and decision-makers as they evaluate challenges at the organizational and clinical levels.

In tailoring the framework to meet individual program needs, the importance of competencies can be identified by asking the following questions:

- What is most important in the individual role?
- What is the professional practice of the navigator?
- What are the overall priorities of the program or system?
- What are the existing strengths and weaknesses in the system?
- What is the current development plan?
- What feedback has been received previously?
- What assessments have been performed?

Functions within each competency can similarly be tailored to reflect:

- Components of the individual role (e.g., work in the community or clinical setting)
- Resources and services
- Individual role descriptions

Regardless of professional background, a professional cancer navigator must possess clinical expertise in oncology, have highly developed therapeutic communication and problem-solving skills, and have a broad knowledge of the health care system and cancer resources (White and Hall, 2006). The functions of a professional navigator go beyond the role of case manager to correspond to a more comprehensive medical or social model of case management based on a patient-centered philosophy of care.

Chapter 2: Peer/Lay Navigation

The role of peer/lay navigator has emerged as a new domain of practice in the field of Navigation. The distinctions between professional and peer/lay navigators are laid out in the Navigation Grid (see Appendix A). Peer/lay navigators focus on providing support and information to patients and families, and facilitating access to services and resources. Peer/lay navigators are available to patients over a period of time, as delineated by the program parameters. The approach is person-centred, where the priorities and concerns of patients and families guide interactions.

Activities in the field of peer/lay navigation have focused on designing programs, developing training materials and evaluating programs. In a survey prepared for a National Navigation Workshop hosted by Cancer Journey, eight programs were identified across the country in 2011: four peer Navigation programs for women's cancers, two peer programs for Chinese cancer patients, and two volunteer programs targeted to high-needs tumour group patients, such as lung, colorectal and brain cancers (Cancer Journey, 2011).

Peer/lay Navigation is in the early stages of development. Following is a brief review of the research literature about peer/lay Navigation in Canada and the United States. There are also examples of volunteer programs in Canada.

Program Design and Navigator Role

In a review of three peer/lay Navigation programs in Canada, each program's design was contingent on careful assessment and consideration of gaps in service and the particular needs of the patient population (Lorhan, Fitch, Cleghorn et al., forthcoming). Peer/lay Navigation programs are designed to address a specific gap in care over a certain phase of the care trajectory. The design of the program is what distinguishes peer/lay Navigation from peer support programs. A peer/lay Navigation program in the cancer centre in Victoria, British Columbia, was designed to provide non-medical sup-

portive care to lung and colorectal patients in transition from diagnosis to the first appointment with an oncologist. The program focuses on facilitating the transition between primary care and oncology for high-needs cancer patients. In Newfoundland and Labrador, provincial needs assessments identified gaps in access to support and services for women with cancer living in rural and remote communities. A peer Navigation program was developed to provide better access to information and support for women with cancer. In Toronto, Ontario, a peer program was established to address information and supportive care needs for Chinese women with breast cancer, as this group was notably underserved because of linguistic and cultural barriers (Lorhan et al., forthcoming).

Each of the three programs uses a different model of intervention designed to suit the local context and local patients' needs, and requires a different type of volunteer. In Victoria, the volunteers need not be a "peer" based on cancer experience, gender, age, culture or any other factor. The lay volunteers in the cancer centre are screened to assess their skills and their ability to offer a higher level of support to cancer patients. The community-based rural program in Newfoundland requires volunteers who are already active and connected in their home communities. The volunteers are peers in that they have experienced cancer either themselves or as a caregiver. In Toronto, the linguistic and cultural mandate of the program means that volunteers must be able to mediate between Chinese and English-Canadian languages and cultures.

In the literature, the volunteer Navigation role is often designed to provide support from a peer who has been through the same illness (Till, 2003) and, in the case of underprivileged groups, one who comes from the same community or ethnic background (Steinberg, Fremont, Khan et al., 2006; Burhansstipanov, Wound, Capelouto et al., 1998; Freeman, 2006; Fiske and Brown, 2008). The fact that volunteers are also being trained to support high-needs cancer patients suggests that peer/lay navigators can be trained to address more complex cases.

Training

Descriptions in the literature note that training for peer/lay navigators normally addresses communication skills, listening and sensitivity, ethics, patient confidentiality, background about basic aspects of cancer diagnoses and treatments, and related emotional and psychosocial issues (Steinberg et al., 2006; Giese-Davis, Bliss-Isberg, Carson et al., 2006). Some training also offers professionally led mentoring or support programs for peer/lay navigators (Giese-Davis et al., 2006; Hohenadel, Kaegi, Laidlaw et al., 2007) and some include training in diversity (Hohenadel et al., 2007; Jandorf, Gutierrez, Lopez et al., 2005).

In the Canadian programs, training emphasizes role definition, scope of practice, cultural awareness, communication skills and cultural barriers. The program in British Columbia included developing a competency framework to assist in screening and train-

ing volunteers. The competency framework included three domains: Self-as-Navigator, Communication and Knowledge/Information (Lorhan et al., forthcoming).

Ongoing support for peer/lay navigators is necessary. In the Canadian programs, supervision is provided, as are regular debriefing sessions. The cost advantages of using volunteers in this capacity must be reconciled with the need for professional supervision and support. The cost-effectiveness of volunteer Navigation is an area for future study.

For more information about the BCCA Volunteer Navigation Position Description, see Appendix L. For more information about the BCCA Volunteer Navigation Program, contact Shaun Lorhan (slorhan@bccancer.bc.ca)

Evidence and Evaluation

There are few models to evaluate whether or how peer/lay Navigation makes a difference in people's treatment experience, quality of life, survival or other aspects of the cancer journey. Further, little is known about its benefits compared to professional models. To date, the evidence does not support one model over another. Giese-Davis et al. (2006) claim evidence from their study shows peer navigators help reduce distress. Hohenadel et al. (2007) found that patients from their pilot program reported important implications for emotional and physical health. Programs in which peer/lay navigators have been used to recruit participants for screening have found that screening rates improve (Freeman, 2006; Jandorf et al., 2005; Burhansstipanov et al., 1998). Importantly, evidence from various programs suggests that peer/lay Navigation helps reduce barriers for marginalized populations (Freeman, 2006; Steinberg et al., 2006; Burhansstipanov et al., 1998).

In Canada, evaluation has focussed on feasibility of and satisfaction with peer/lay navigator training. The findings are limited because the peer/lay programs are very small and the evaluation tools are variable. More needs to be done to develop knowledge in this field. The Cancer Journey Program Logic Model and the Cancer Journey Quality Improvement and Evaluation Framework can be adapted for peer/lay Navigation programs to provide a starting point for more robust evaluation (see Appendices B and J).

Conclusion

Peer/lay Navigation programs have, understandably, responded to particular needs in different contexts without waiting for standardized models and often with limited resources. It seems that the task at hand is to continue to learn from their successes and challenges and to maintain flexibility to differing needs, even while the service is consolidated and systematized.

Chapter 3: Virtual Navigation

In May 2009, the Partnership commissioned a pilot study to understand how virtual Navigation (navigating the cancer journey using internet support) can support cancer patients. Specifically, the pilot evaluated the introduction of the Oncology Interactive Navigator™ (OIN) tool in seven cancer centres across Canada. Findings from this study are meant to help partner organizations (i.e., provincial cancer agencies and cancer centres) assess the applicability and appropriateness of introducing the OIN as a virtual Navigation tool in routine cancer care. When the pilot was initiated, the OIN was the only comprehensive tool available in Canada that was designed to support virtual navigation for cancer patients. Now, there are a number of web-based tools that include features such as a repository of clinical trials, and monitoring, record keeping and communication devices designed to help patients manage their cancer experience.

In addition to peer and professional Navigation (help navigating the cancer journey from cancer survivors and cancer care professionals), virtual Navigation is recognized as an important component of patient Navigation overall, particularly as more and more patients and their caregivers seek web-based resources to manage their cancer experience.

Findings from this pilot study suggest that a high-quality e-health application is well received by people affected by cancer. Preliminary findings also suggest positive trends in terms of the effects of the OIN on patient empowerment based on cancer competence, support for patient autonomy, involvement in decision-making and enhanced cancer knowledge. In addition, complementary qualitative findings support the tool as a relevant, timely and important resource for patients and families. Automatic tracking data (a more objective measure of OIN use) provided by Jack Digital Productions Inc. and analyzed by the research team corroborated the findings that the OIN is an engaging e-health application.

Successful implementation of the OIN requires that all the components of any change in practice be addressed. Sufficient resources, committed champions, engaged clinical teams, and a dedicated clinic assistant or volunteer to approach patient and family members to encourage OIN use were cited as key factors in successful implementation. Even seemingly minor activities that interrupt the current flow of busy clinic activities are destined to meet with resistance without a well thought out implementation plan, no matter how novel or innovative or engaging a new patient service or resource might be.

Now that this pan-Canadian pilot has been completed, the full report, [Virtual Navigation in Cancer: A Pilot Study](#) is available to provincial and territorial cancer organizations to assess the appropriateness of introducing a virtual navigation tool in their local settings.

Additional Activities in Virtual Navigation

According to reports gathered from across Canada in the fall of 2011 about developments in Navigation, several provinces indicated interest in creating personal health portals to enhance patients' ability to self-navigate. The portals are expected to improve patient engagement and self-management of care, and improve the patient experience by providing easy access to credible cancer information (Cancer Journey, 2011).

Chapter 4: Practice Change

Early in Cancer Journey's mandate, a national working group was brought together to develop the Navigation Grid (see Appendix A). The grid provides a definition and vision for Navigation, and describes the characteristics, scope of practice, skill and training requirements, and possible outcomes for professional and peer/lay Navigation. The document defines the vision for Navigation as follows:

Navigation is part of an integrated system of cancer service delivery. Navigators work with the person and family and their interdisciplinary team to assess needs, provide supportive care, answer questions, identify and address any barriers to quality care, and facilitate access to needed resources and services. Navigation aims to improve both coordination in services and continuity throughout cancer care, as well as quality of life for the person and family throughout the cancer journey.

To achieve a vision of person-centred care, a change in health care culture is required and this change can only be achieved by changing practice. Health care professionals must broaden their perspectives to see the whole person and work collaboratively to meet the full range of each patient's needs. The interprofessional team needs to work in partnership with the navigator, the cancer patient and their family to ensure that care is responsive and tailored to the specific needs of each patient and family.

To reach this vision of person-centred care, a programmatic approach to Navigation should be used. A programmatic approach is the planned and systematic process of implementing an evidence-based intervention that engages all relevant stakeholders within and outside of the institution. Stakeholders share a common vision and objective and have a clear perspective on the results of the initiative. A programmatic approach is a process that aims to embed the intervention in a comprehensive and sustained manner, where the final result is systemic change in health care capacity, practices and performance (Swerrison, Duckett and Daly, 2001; Walters, 2011).

A programmatic approach is recommended for implementing Navigation because changing practices is a complex process. Navigation is a means of improving health-related quality of life and patient outcomes, while also enhancing professional practice based on research evidence. Achieving these aims is a significant amount of work that requires

a planned and programmatic approach. The implementation of Navigation can be one of the drivers in the shift toward a more person-centred cancer care system.

Implementation is defined as “a specific set of activities designed to put into practice an activity or program of known dimensions.” (Fixsen, Naoom, Blasé, et al., 2005) The challenge is to craft an implementation plan that takes into account, as much as possible, the known dimensions of the new program and activity, as well as the known dimensions of the potential adopters and their practice environment. Once the innovation and the local context are well understood, an implementation plan can be put into place. Enacting the implementation plan requires knowledge, skills and strategies regarding change management.

The purpose of this chapter is to explore the dimensions of the task at hand (implementing Navigation) within the unique context of the local setting. A Navigation Program Logic Model has been developed to outline the general components, inputs, activities, outputs and various outcomes associated with implementation (Appendix B). The logic model can be adapted to suit the local context and is a key component of implementation planning and execution.

The planning and assessment phase is the beginning of stakeholder engagement in the implementation process, the beginning of field preparation and the beginning of change management. A thorough assessment and understanding of local factors are central to developing a systematic and well-informed implementation strategy and plan. At the same time, the process of implementation requires constant change management, and the tools and resources in this chapter can assist with assessing the local capacity for change, and the skills and knowledge required to manage it. The following sections present some basic principles of change management, followed by some tools to help prepare the management team to lead, facilitate and drive the desired change in practice.

About Managing Change: Key Principles

The following list is derived from the Change Management Toolkit (London Borough of Lambeth, 2007), which is a useful resource for any project.

- Think big, act small. Keep the big picture or vision in mind at all times, but make sure that all stakeholders and individuals have their say and are allowed to contribute.
- Go where the energy is. Try to work with the most energetic and enthusiastic staff at the early stages to make sure that things happen. The 30:40:30 rule is often invoked to encourage a realistic focus on change. The leading 30% of staff (proportions may vary) are usually prepared to support and participate in change. If they get convincing early results, the next 40% can probably be persuaded to embrace change and this is where the main effort needs to be applied. For the remainder, it

See the [Change Management Toolkit](#) for more tools and tips to manage change.

is reasonable to insist on compliance but they are unlikely to accept the arguments for change.

- Help and support is required after initiation as well as before.
- Do not think you can build ownership at the beginning of a change. Involve people throughout the development process.
- Beware of “brute sanity.” One of the things that many managers do when trying to promote change is to give lots of clear, loud messages to staff about how wonderful the innovation is, how it will revolutionize the service, etc. This is brute sanity. If the messages are said often enough and loud enough, staff will tend to back off and build barriers.

Guiding Principles of Knowledge Implementation

In the national evaluation of Cancer Journey implementation initiatives across Canada, the evaluators established nine guiding principles of knowledge implementation based on change management literature. Change management knowledge, skills and strategies are recognized as integral to successful implementation of innovative programs. These principles are designed to be used as a package, and thus *all* principles should be applied to achieve full knowledge implementation and to ensure that managing change is as effective as possible. For definitions of each principle, see Appendix C.

Guiding Principles of Knowledge Implementation

1. Problem Assessment and Understanding
2. Tailoring to Local Context
3. Assessment of Individual Perceptions and Motivations
4. Barrier Identification and Management
5. Identification of Social Influences
6. Training and Coaching
7. Organizational Capacity Building and Infrastructure Development
8. Patient Engagement and Implementation
9. Monitoring, Evaluating, Reporting, Disseminating

PricewaterhouseCoopers LLP, 2010b

The Foundations of Implementation Planning

The following information is intended to guide the management team through some steps to assess and plan for implementation.

As a first step, the management team needs to gather evidence to support the need for Navigation. How is the clinic or team currently practicing? How satisfied are the patients with the experience of care? What are the gaps or bottlenecks in care processes? The answers to these kinds of questions can be used to create key messages about how Navigation can solve problems for the patients, staff, organization, external stakeholders and health care system. Some of this data may already be available from existing surveys, patient data or other sources, but it may need to be collected. Data may be useful to provide a pre-implementation baseline. See *Chapter 6, Quality Improvement and Evaluation*, for more information on data collection.

Gather Evidence

- Picker surveys or other patient surveys
- Needs assessment and gap analysis
- Baseline data from clinics and disease site groups

Next, the management team should assess organizational readiness for change, beginning with a self-assessment. Does the management team have the knowledge, skills and expertise to effectively manage change? (See Appendix D: Self-assessment of Change Management Skills for a tool that can be used with individuals and groups.) If these skills are lacking, the team might consider how to build such capacity, as described below.

Leadership, Change Agents and Facilitation

Implementing and adapting Navigation is a change process that must be active, managed and participatory. Key components of the process are leadership, change agents and facilitation (Harrison and van den Hoek, 2010).

Leadership: Senior management must lead the change and their commitment is vital (Ellis and Kiely, 2000):

- To enable the change process
- To ultimately be accountable and responsible for initiating and guiding the change process

Change Agents: Change agents are central to the process of managing change effectively. A change agent is an “an individual who influences clients’ innovation decisions in a direction deemed desirable by a change agency.” (Stetler, Legro, and Rycroft-Malone, 2006) Change agents:

- Take the change forward
- Provide the right blend of support and pressure to motivate staff
- Maintain momentum

A great deal has been written about the skills and qualities needed to be a good change agent, and learning to be an effective change agent is important.

Facilitation: A key role of a change agent is facilitation. Facilitation is defined as “the process of enabling (making easier) the implementation of evidence into practice.” It is “a deliberate and valued process of *interactive problem solving and support* that occurs in the context of a recognized need for improvement and a supportive interpersonal relationship.” (Stetler et al., 2006)

The facilitator role is about supporting people to change their practice (Harvey, Loftus-Hills, Rycroft-Malone et al., 2002):

- It is an appointed role
- It is about helping and enabling versus telling and persuading
- It ranges from providing help to achieve a specific task to using methods that enable individuals and teams to review their attitudes, habits, skills, and ways of thinking and working

In their 2010 article in *Worldviews on Evidence-Based Nursing*, Doherty, Harrison and Graham (2010) outlined the activities involved in facilitation in a table titled Taxonomy of Facilitation Interventions/Strategies and Facilitator Role Synopsis. The key activities and skills of facilitation are:

- Planning for change
 - Increasing awareness
 - Developing a plan
- Leading and managing change
 - Managing knowledge and data
 - Managing the project
 - Recognizing the importance of context
 - Fostering team building and group dynamics
 - Supporting project administration
- Monitoring progress and ongoing implementation
 - Problem solving
 - Supporting
 - Effectively communicating
- Evaluating change
 - Assessing

The following are assumptions that a facilitator must or must not make (London Borough of Lambeth, 2007):

- Do not assume that your version of what the change should be is the one that could or should be implemented.
- Assume that, to result in change, any significant innovation requires individual adopters to work out their own meanings.
- Assume that conflict and disagreement are not only inevitable but fundamental.
- Assume that people need pressure to change but that it will only be effective under conditions that allow them to react and form their own positions.
- Assume that real change takes time – a minimum of three years.
- Do not assume that lack of implementation is outright rejection of the values embodied in the change.
- Do not expect everyone to change.
- Assume you will need a plan and that it is essential to have knowledge about the change process.
- Assume that no amount of knowledge will ever make it totally clear what action should be taken.
- Assume that change is a frustrating, discouraging business.

Once the management team has assessed its own skills and knowledge in change management, it is time to assess the readiness of the organization and the staff within it.

Assessing Individual Perceptions and Motivations; Identifying Barriers

The need to assess individual perceptions about and motivation for the uptake of new knowledge and practices cannot be under-estimated. The results of such an assessment provide the foundation for identifying receptivity for and barriers to change at both the level of the individual and the organization. Identifying barriers is an essential step in implementation because it allows change agents to discover and anticipate, as much as possible, the hurdles that may occur in moving forward with practice change. Knowledge of some of the barriers that are present means that implementation can be tailored with strategies that address those barriers. Experts in organizational change contend that readiness to change is critical to successful implementation of new practices (Hagedorn, Logan, Smith et al., 2006).

Individual and Staff Assessment

The Readiness for Change Checklist (see Appendix F) is an excellent place to start to assess staff preparedness for, and attitudes toward, the implementation of Navigation. Assessment can include, for example, an examination of individual values, belief in the credibility of the new knowledge that staff are being asked to adopt, behaviour toward sustaining the knowledge, beliefs about staff capabilities and confidence, the emotional response to the knowledge, and the place of the initiative among competing priorities. Various methods for collecting this information are discussed below.

Assessing the Practice Environment

What does a practice environment that is really ready for change look or feel like? Ten features of an adaptive practice environment are shown below. The quotes beside each are typical of the sorts of things that people will say if they are working in an adaptive work setting (adapted from Stoll and Fink, 1996):

- Shared goals “We know where we’re going”
- Responsibility for success..... “We will make this work”
- Collegiality “We’re in this together”
- Continuous improvement “We can still do better”
- Lifelong learning “Learning is for everyone”
- Risk taking “We learn by trying something new every day”
- Support “There’s always someone there to help”
- Mutual respect “Everyone has something to offer”
- Openness “We can discuss our differences”
- Celebration and humour “We are a good team”

Practice environment factors can facilitate or constrain the uptake of new practices. Factors to consider are listed below (Logan and Graham, 1998):

- Structural factors
 - The decision-making structure
 - Rules
 - Regulations
 - Official policies
 - The physical structure
 - Workload
 - Resources
 - Supplies
 - The system of incentives
- Social factors
 - The politics and personalities involved
 - The presence of local champions or advocates of the innovation
 - The culture and belief systems operating within the setting
 - Culture is about how things are done within your practice environment and is heavily influenced by shared unwritten rules. Unwritten rules are one of the most powerful parts of culture. They are described as “unwritten” because they are:
 - Not often openly discussed in meetings and formal documents
 - Rarely questioned or challenged because they are not frequently discussed
 - Usually shared by most, if not all, the people who work within the team

- Provide a common way for people to make sense of what is going on around them, to see situations and events in similar ways, and behave accordingly
 - Often influence people without them necessarily realizing it
 - Have a powerful influence on how people behave at work
- Patients
 - Patient influence or pressure may stimulate practitioner adoption of guidelines while patients' inability or unwillingness to comply with guideline recommendations may discourage practitioners from applying the guideline
 - Other
 - Medico-legal issues

Equipped with an understanding of the types of barriers faced by health care practices generally, the management team now needs to look at the specific barriers in the practice environment. Management can use a number of methods to identify where change is needed and potential barriers to that change. The choice of method should be guided by local context, including the number of people involved, the time and resources available, acceptability, accuracy, generalizability, reliability and cost. In some situations, more than one approach may be needed. See Appendix G for a more detailed version of the following methods of examining barriers, including advantages and disadvantages of employing these methods. This section is adapted from "How to Change Practice," a guide from the National Health Service (NHS) in the United Kingdom (NICE, 2007).

Methods for Examining Barriers

Talk to Key Individuals: Key individuals have specific understanding of a given situation and have the knowledge, skills and authority to think about a topic and explore new ideas. The change management team may want to consider talking to a group of key individuals at one of their regular meetings, such as a staff meeting. (NICE, 2007)

Observe Clinical Practice in Action: Sometimes the best way to assess current clinical practice is by observing individual behaviours and interactions. This is especially appropriate if you are looking at events that happen quite often. A more formal way of doing this is through a chart audit. (NICE, 2007)

Use a Questionnaire: A questionnaire is a good way to explore the knowledge, beliefs, attitudes and behaviour of a group of geographically dispersed health care professionals. Careful thought needs to be given to the design of the questions, as the quality of the answers relies heavily on the quality of the questions. Both electronic and paper formats can be used to encourage responses. (NICE, 2007)

Brainstorm: Brainstorming is a way to develop creative solutions to problems. It can be done informally in small groups or using a focus group. The session starts with an outline of the problem and then participants are encouraged to come up with as many ideas as possible to solve it. One of the great things about brainstorming is that participants can bounce ideas off each other and develop and refine them further. www.brainstorming.co.uk provides free online training in brainstorming, including the rules of brainstorming and running a brainstorming session. (NICE, 2007)

Run a Focus Group: Focus groups are a powerful means of evaluating current practice and testing new ideas. They are a facilitated discussion with a group of six to 10 people. Open questions are posed by the facilitator, who then encourages the group to discuss their experiences and thoughts, and reflect on the views of others. (NICE, 2007)

Case Studies: Case studies are useful when very detailed information about a past event may shed light on existing barriers. (NCIS, 2006)

Interviews: A face-to-face, one-on-one discussion with individuals who are asked specific questions by an interviewer. Interviews can be unstructured, semi-structured or structured. (NCIS, 2006)

Surveys: A survey is a standardized set of questions to assess participants' knowledge, attitudes and/or self-reported behaviour. The questions can be open ended, allowing participants to report their responses verbatim; closed, requiring participants to select answers from a predetermined list; or a combination of both. (NCIS, 2006)

Nominal Group Technique: The Nominal Group Technique is a highly structured discussion among a group of people whose ideas are pooled and prioritized. (NCIS, 2006)

Delphi Technique: The Delphi Technique is an iterative process in which information is collected from the same group of participants through a series of surveys. (NCIS, 2006)

Arts-Based Techniques: Arts-based approaches to examining barriers offer the potential to foster critical awareness, to facilitate understanding and to nurture sympathy. Dramatic performances have successfully helped health care professionals reflect on the care they provide and increase their understanding of patient care issues (Kontos and Poland, 2009).

The Process and Plan

Promising practices collected from the jurisdictions implementing Navigation show that a phased and systematic approach is required to effectively initiate a Navigation program (Consultation Nicolas Inc., 2012). Key elements of a phased approach to implementation include:

- Selecting one clinic or disease site group that exhibits the greatest readiness to begin implementation, followed by the next site that is most ready.
- Creating an inclusive implementation team comprising staff representatives from the clinic or disease site. The team must have regular meetings about the process and plan for implementation and should have significant decision-making authority (within set parameters) about how the new practice will be integrated with the current health care environment.
- Working together to create a timeline and process map to implement Navigation. The plan needs to include assigned responsibilities for each task with regard to the steps and activities for implementation, data collection, communication and reporting, and budgeting.
- Reporting successes early and often to the sites, the administration and to community partners to keep the program “top of mind.”

This chapter has provided a review of the key components to the planning and assessment phase of implementing Navigation. The topic of implementation continues in Chapter 5. By completing activities noted in this section, the management team has:

- Established how Navigation can address local needs (problem assessment and understanding)
- Assessed the organization’s capacity to lead and manage practice change (self-assessment of change management skills and the facilitator role)
- Assessed barriers in the individual adopters and in the practice environment (assessment of individual perceptions and motivations and barrier identification and management)
- Tailored the Program Logic Model to suit the local context
- Created a phased approach to implementation, selecting clinics or disease sites based on readiness and enthusiasm to integrate Navigation

Practice change that relies heavily on human interaction requires clear communication, a clear theory of change that makes the case for the change, and champions who consistently advocate, cajole, recognize, reward and encourage.

E.M. Rogers, 2003

Chapter 5: Promising Practices in Implementing Navigation

The previous chapter provided some tools and information about a change management approach to implementation. This chapter addresses promising practices in implementing professional and peer/lay Navigation programs, including selecting program teams and defining program parameters. The chapter also addresses learnings and strategies for successful implementation from a national evaluation of three Navigation programs (Consultation Nicolas Inc., 2012).

Team Selection

One of the first steps in moving Navigation forward is creating a management team and establishing a steering group.

Management Team

The management team typically consists of the lead, co-leads and coordinator or manager.

Steering Committee

A steering committee is vital to gathering support and directing the implementation. All members of this committee should act as visible champions of the program. Ideally, the committee includes members from all levels of care and throughout the continuum of care, such as administration, interdisciplinary health care professionals and support staff, as well as members of the community. If possible, individuals who inspire and motivate others are part of this group. It may be useful to engage high level administrators in choosing individuals for the steering committee (most steering committees meet on a quarterly basis). It is helpful to have representatives from information technology and who have research and evaluation backgrounds.

To assist with program planning, Cancer Journey has developed a Navigation Program Logic Model (see Appendix B).

The logic model presents seven key program components and the corresponding resources, key activities, outputs, process outcomes, and the short-, intermediate- and long-term outcomes. The logic model serves as a blueprint for planning purposes and can be adapted to and specified for the local context.

Implementation Team

In general the implementation team varies from the steering group in that it comprises more front line staff and individuals representing groups directly involved with implementation. The following are some the groups or representatives that could be included:

- Management team: coordinator and lead(s)
- Representatives from the area where implementation is beginning (e.g., representative from the tumour group or clinic)
- Front line staff member
- Oncologist
- Nurse educator
- Manager for relevant areas of implementation
- Administrative representative (e.g., unit clerk)
- IT representative

It is advisable to have the implementation team meet once a week or once every two weeks in the development and early implementation stages. This can be adjusted to once a month once Navigation is established.

Planning Parameters

The management team will determine who the program is for (target population), at which point in the care trajectory (diagnosis to treatment, treatment phase, etc.) and the desired outcomes. Implementing Navigation requires a planned programmatic approach to ensure that the desired outcomes are reached. The approach suggests that the management team needs to adequately assess readiness for change in the practice environment, to consider the barriers to change and to devise strategies to alleviate these barriers. This is the period of field preparation, where the management team focuses on the activities required to build the capacity of the practice environment to support Navigation.

As field preparation begins, the management team plans a systematic and phased approach to rolling out the new initiative. This means that the roll out of Navigation begins with a local team that demonstrates high interest and engagement in the prospect of Navigation, with perhaps one navigator, to test and assess the changes in roles and processes. Roll out then continues to expand across the site in this phased approach.

The key program components, as detailed in the Navigation Program Logic Model (see Appendix B), are laid out in the following table, with some key considerations for each (Cook, 2012).

Table 2: Program Components and Considerations

| Component | Considerations |
|--|---|
| Planning and Assessment | <ul style="list-style-type: none"> • Establish a change management approach to implementation. See Chapter 4 for guidance. |
| Staff Training and Support | <ul style="list-style-type: none"> • Focus on orientation to the role and developing navigators' skills: <ul style="list-style-type: none"> – Embed as members of multidisciplinary team – Connect to key people in the hospital or cancer centre and community – Ensure that Navigation is part of all continuing education regarding oncology – Create a navigator community of practice for problem solving and peer consultation and support – Implement evidence-based care pathways and clinical practice guidelines (for professional navigators) – Build awareness of and education about the navigator role and scope of practice among interprofessional teams and community partners |
| Teamwork and Collaboration | <ul style="list-style-type: none"> • Assess readiness for adoption of Navigation by local health care teams • Develop strategies and interventions to raise awareness of Navigation within interprofessional teams and to provide education • Allow collaborative development of care paths and other processes |
| Organizational Capacity Building | <ul style="list-style-type: none"> • Identify your stakeholders and community partners • Identify local and regional resources available to navigators • Identify community resources to meet supportive care needs of patients • Mobilize community resources where there is a gap (e.g., peer support groups) |
| Patient Engagement | <ul style="list-style-type: none"> • Develop a marketing strategy • Develop branding • Communicate at every opportunity to local audiences (e.g., newsletters, radio and websites) • Develop patient education materials |
| Monitoring, Evaluating, Reporting, Disseminating | <ul style="list-style-type: none"> • Create program logic model, implementation and evaluation plans • Document your processes • Develop tools: screening, assessment, charting and sharing information, consent forms • Have forms approved • Draft confidentiality policies and procedures • Establish a referral system, standards for care and triage criteria • Create consultation and follow-up procedures • Create a budget and reporting process • Establish data collection and information management systems |

Key Findings from the National Evaluation

Cancer Journey partnered with three jurisdictions to implement sustainable Navigation programs. The focus of the evaluation was the key activities and lessons learned by the jurisdictions in the process of implementation (Consultation Nicolas, 2012). The partnership lasted a year and a half so that the period of implementation could be observed and evidence of sustainability evaluated. The following briefly describes the programs and key findings.

Programs

BC Cancer Agency Lay Navigation Program

The Lay Navigation Program provided non-medical support to newly diagnosed colorectal and lung cancer patients in an urban cancer centre. Support was provided by screened and trained volunteers for the period between a patient's initial diagnosis and approximately one week after the initial oncology consult. The Navigation support service was a three-step, time-oriented intervention. The first contact, initiated by the lay navigator, was by telephone; the second was either by telephone or in person (based on the patient's choice). These first two contacts took place between the patient's diagnosis and their first oncology consult. The third (and fourth if necessary) contact occurred by telephone after the patient's first oncology appointment and served to address any emerging concerns and questions the patient had.

The goal of the Navigation support service was to decrease patient distress, prepare the patient for the first oncology consult and the cancer journey, and address barriers to care. The scope of practice of the lay navigator included providing empathic emotional support, determining and addressing barriers to care, encouraging empowerment in accessing care services, and facilitating referrals to reliable resources and services.

Cancer Care Ontario Diagnostic Assessment Program (DAP) Navigation Program

Cancer Care Ontario's DAP Navigation program was a provincial implementation of nurse-led patient Navigation. The navigators were based in cancer centres to support and facilitate the care of lung and colorectal cancer patients during the diagnostic phase. The project objectives were to:

- build capacity in patient Navigation in the diagnostic phase of cancer;
- evaluate the role of nurses as navigators for patients suspected of having cancer as they enter the cancer system.

CancerCare Manitoba Rural Navigation Program

CancerCare Manitoba's program goal was to reduce the challenges and systemic complexities encountered by rural cancer patients and their families. Part-time nurse and social work navigators were based in three regions. The project objectives were to:

- Create and facilitate a streamlined process of care delivery that assists rural patients and their families through the entire cancer trajectory.
- Document challenges faced by patients and their families within the community to identify gaps in services.
- Improve patient satisfaction and reduce specialist requirements by assisting patients after treatment as they transition from their current oncology care providers back to their family physicians.
- Coordinate and facilitate seamless integration of care to ensure timely access to diagnostic procedures, supportive care services and appropriate treatment modalities throughout the illness trajectory.

Key Findings

The following findings are grouped according to the program components of the Cancer Journey Navigation Program Logic Model (Appendix B). The findings are followed by some of the common challenges experienced by the jurisdictions and examples of strategies to address those challenges.

Planning and Assessment

- The jurisdictions selected sites that demonstrated readiness to begin implementing Navigation on a small scale. They planned a phased approach to expanding the programs to additional sites.
- The jurisdictions found that information management and technology issues had the potential to delay timelines. It is important to be aware of this in planning project timelines and targets.

Staff Training and Support

- All jurisdictions developed comprehensive training and orientation sessions for their navigators. This initial education was supported by clinic mentoring and/or supervision, as well as opportunities for continuing education. Training needs to be tailored to the local program and context.
- Establishing communities of practice among navigators was found to be beneficial. Navigators need ongoing support, mentoring, opportunities to share learning and experiences, and access to information and resources related to their work.

- Navigation can be considered a new career option for nurses, with new approaches to providing care and support to patients.
- Volunteers can be trained to provide Navigation services using screening, training and assessment protocols that ensure competency. Volunteers rise to the challenge of high expectations and greater responsibility.
- Rigorous standards to qualify volunteers in the navigator role are essential if volunteer navigators are to be accepted in the organization and to mitigate risk.

Key Changes to Practice with the Implementation of Navigation

- Encourages the shift from a “reactive” to “proactive” model of care
- Promotes self-management and the “expert patient” model
- Encourages interprofessional collaboration
- Fosters integration of cancer surgery in care path
- Promotes involvement and integration primary care professionals

Teamwork and Collaboration

- When well integrated into health care teams, navigators can be catalysts to connecting health care providers and patients and to improving continuity of care.
- Collaborative relationships are encouraged with physicians, nurses and other health care providers, including clerks and administrative assistants, to embed the program in the health care system.
- Implementing Navigation is an opportunity to collaborate and improve relationships with community partners.
- Implementing Navigation is an opportunity to improve interprofessional teamwork and collaboration, and an opportunity to enhance person-centred care.

Organizational Capacity Building

- It is essential to identify and engage champions. Champions should be from all levels and sectors – senior management to front-line staff – in the organization and in the community.
 - Within each of the organizations involved in the evaluation:
 - senior management endorsed the project;
 - dedicated and passionate project leads and coordinators were engaged;
 - partnerships and collaborations were established at the local, provincial and national levels;
 - key stakeholders came together to plan, implement and evaluate the project;
 - locally, as champions were identified, teamwork was facilitated and learning environments were created to maximize the opportunities for success;
 - navigators became role models and mentors for newly hired navigators.

- For navigators based in a rural setting or within the community, a significant focus is outreach in order to establish a referral base. Nurses do not necessarily have the skills to engage the community and develop such referral relationships. However, navigators in the community need such skills. Training in outreach must be incorporated in navigator training, and an ongoing outreach strategy should be a key component of program implementation and sustainability.
- Using peer/lay volunteers in Navigation programs creates a new role and enhanced capacity for volunteers in health care organizations.

Patient Engagement

- The three project sites spent considerable time developing communication strategies and supporting documents (e.g., pamphlets, brochures and information guides) to inform patients about Navigation services. A significant effort was made to collaborate with physicians, nurse practitioners and other health care providers in a position to refer patients to the service. These providers were expected to provide the information to patients and families. In certain instances, navigators attended community events to distribute information and tell the public about Navigation services. Newspapers and other forms of media were also used to inform the public.
- Patients and families and the community are eager for a volunteer navigator role, so organizations need to be prepared for requests from all cancer populations.

Monitoring, Evaluating, Reporting, Disseminating

- Successful implementation requires coordination and communication with all key stakeholders.
- In the field preparation phase of implementation, it is essential to establish methods to log and extract program data. It is beneficial to have an expert in data management on the management team, as well as an expert in evaluation, to mitigate the challenges of data capture and extraction.
- It is critical to collect relevant baseline data. Many institutions have access to some measures of patient satisfaction and experience with care, such as Picker surveys, but sometimes these measures are not specific enough to know if any changes in patient outcomes can be attributable to Navigation.
- Evaluation of Navigation relies on good documentation. The management team may need targeted strategies focused on improving and enhancing documentation of Navigation, since the quality and consistency of data relies on this documentation.
- It is important to have realistic expectations about when changes in practice or in patient outcomes are perceptible. Change in practice and in patient outcomes takes a lot of time, and thus its effects will take some time to detect as well.

See the [Cancer Patient Navigation Evaluation Report](#) from Care Nova Scotia for examples of evaluation tools.

- In the first few years of a Navigation program, it is helpful to focus the evaluation on a small set of carefully selected outcomes. Most jurisdictions implementing Navigation begin by assessing patient and staff satisfaction. While more challenging to measure, a system-based indicator such as reduction in wait times is also effective.

See Chapter 6 for more information about evaluating Navigation programs.

Common Challenges and Strategies

| Challenges | Strategies to Address Challenges |
|--|---|
| Increasing workload for navigator | Separate clinical from clerical tasks and provide additional support for clerical tasks, if possible. |
| Belief that the new navigator role <ul style="list-style-type: none"> – will replace existing positions – is redundant – is a “band-aid” solution | Multiple approaches are needed to raise awareness of and educate health care teams about the new role: <ul style="list-style-type: none"> – Take a patient-centred approach to emphasize how the role can change patient outcomes – Foster staff engagement in the implementation process to unearth concerns early on (meet directly with individual[s] and discuss scope of practice and other concerns) – Address concerns with case examples and research evidence |
| Physician support of Navigation | Engage physicians early in the field preparation and planning phases. Work to establish relationships with primary care providers, using multiple strategies to raise awareness, educate and market (e.g., staff meetings and organizational partnerships). |
| Geography | Navigators in rural regions have time, travel and budgetary limitations. Telephone and telehealth videoconferencing are required tools for practice and there must be protocols to assess these tools and intervene as necessary. |
| Referrals | An ongoing and effective marketing plan is required to encourage referrals to a new Navigation program. Ideally, 100% of patients are routinely informed about the availability and function of Navigation services. If responsibility for marketing is a component of the navigator role, these skills must be included in training. |
| Concerns about the availability of psychosocial and supportive care and unmet patient needs | Prepare an inventory of hospital and community-based resources in the field preparation stage. Collaborate with local teams to establish care pathways (if not already in place). Initial and ongoing education and training for navigators should include reviews of local resources. Communities of practice must have mechanisms to share information about local resources. Navigation is an opportunity to document, track, identify and advocate for service gaps and inefficiencies. Develop mechanisms to document and report these system-level gaps. |

Integrating Screening for Distress, The 6th Vital Sign

Cancer Journey's initiative in Screening for Distress dovetails with that of Navigation, where professional navigators have begun to integrate the Screening for Distress tools. Using simple and validated tools, Screening for Distress involves identifying a patient's key concerns. Understanding these concerns allows health care professionals to recognize whether a patient needs further assessments and appropriate referrals to specific resources, such as pain control or a psycho-educative group. Screening clearly differs from assessment, which is conducted after screening and involves a more comprehensive and focused examination of the patient's situation.

The experience of implementing Screening for Distress with navigators in Quebec and Nova Scotia has been qualitatively evaluated. Fillion et al. (2011) found that the tool was well received by navigators, who were well positioned to take up Screening for Distress because of their expertise in psychosocial and supportive care. Screening for Distress was found to help navigators with the key functions of screening and assessment, coordination of care, patient empowerment and professional collaboration. Findings also showed that health care administrators supported the integration of Screening for Distress with Navigation as a means to improve efficient use of resources and quality of care. The study results are useful for those planning to implement Screening for Distress with navigators because they provide a thorough analysis of the implementation of the screening tool in the context of Navigation (Fillion, Cook, Blais, Veillette, Aubin, de Serres, Rainville, Fitch, Doll, Simard and Fournier, 2011).

Cancer Journey Portfolio Resources: Screening for Distress, The 6th Vital Sign

- Screening for Distress, The 6th Vital Sign: A Guide to Implementing Best Practices in Person-Centred Care, 2012
- [Pan-Canadian Clinical Practice Guidelines](#)
- Pan-Canadian Clinical Practice Guideline Protocols for telephone/internet support (in [English](#) and [French](#))

Two of the jurisdictions integrated Screening for Distress into routine practice with navigators. For one jurisdiction, "the experience of implementing COMPASS Screening for Distress and Navigation at the same time, emphasized the potential for success and maximized the opportunity to build person-centered, comprehensive cancer care in rural Manitoba." (CancerCare Manitoba, 2012)

Chapter 6: Quality Improvement and Evaluation

Cancer Journey's Quality Improvement (QI) and Evaluation Team developed a framework for implementing and evaluating Navigation for the jurisdictions involved in the national initiative. The framework outlines the key areas for collecting evaluation data – including mechanisms to monitor progress and make course corrections as necessary to ensure that program goals and targets are being reached (continuous quality improvement). See Appendix J for the Navigation Quality Improvement and Evaluation Framework.

Quality Improvement and Evaluation Framework

Cancer Journey's framework recommends beginning by collecting baseline data prior to implementation using standardized measurement tools. These tools are used again after Navigation has been fully implemented to evaluate the implementation. Baseline data collection can also be built into the planning and assessment phase. The key areas for data collection are:

- Staff knowledge and skills
- Staff satisfaction
- Patient satisfaction and experience
- Organizational culture (team collaboration)

The framework depicts the four key components for implementing Navigation. The elements of the Navigation Program Logic Model (Appendix B) that correspond to the framework components are shown in the following table.

Program Components

| QI and Evaluation Components | Program Logic Model Components |
|------------------------------------|--|
| 1. Navigation | <ul style="list-style-type: none"> • Planning and Assessment • Organizational Capacity Building • Monitoring, Evaluating and Reporting • Disseminating |
| 2. Education and Training | <ul style="list-style-type: none"> • Staff Selection, Training and Support |
| 3. Teamwork and Collaboration | <ul style="list-style-type: none"> • Teamwork and Collaboration |
| 4. Patient Engagement and Outcomes | <ul style="list-style-type: none"> • Patient Engagement and Outcomes |

The Quality Improvement and Evaluation Framework assigns aims (targets) in four areas. The aims are intentionally high and exist as a goal or target for the management and implementation teams to reach for.

Components and Aims

| QI and Evaluation Components | Program Logic Model Components | Aim(s) |
|------------------------------------|--|--|
| 1. Navigation | <ul style="list-style-type: none"> • Planning and Assessment • Organizational Capacity Building • Monitoring, Evaluating and Reporting • Disseminating | <ul style="list-style-type: none"> • 90% of target group is informed about Navigation function and availability |
| 2. Education and Training | <ul style="list-style-type: none"> • Staff Selection, Training and Support | <ul style="list-style-type: none"> • 90% of navigators hired have knowledge and skills required for scope of practice • 90% of other health care providers have knowledge and skills to facilitate integration of Navigation in team practice |
| 3. Teamwork and Collaboration | <ul style="list-style-type: none"> • Teamwork and Collaboration | <ul style="list-style-type: none"> • 90% of navigators and other health care team members use best practice guidelines • 90% of navigators and other health care staff report a high degree of satisfaction with integration of Navigation in team |
| 4. Patient Engagement and Outcomes | <ul style="list-style-type: none"> • Patient Engagement and Outcomes | <ul style="list-style-type: none"> • 90% of navigated patients/families are satisfied with process of care |

Quality Improvement

Quality improvement offers a proven methodology for improving care for patients and for improving staff practices. It is a continuous process of identifying areas where process changes are needed and monitoring progress in the implementation of those changes. The implementation of Navigation is an opportunity to streamline and improve the delivery of person-centred cancer care. Continuous quality improvement ensures that

Benefits of Quality Improvement

- Identifies quality issues
- Clarifies perceived and actual service delivery
- Tags and tracks indicators to know if change is an improvement
- Provides data on early gains
- Allows change with little risk to patients or of service disruption
- Allows shared learning and motivation
- Promotes quality activities to all stakeholders

Powell, Rushmer and Davies, 2009;
Rushmer and Voigt, 2008

the changes that are being made are in fact improvements, and that the changes being made lead to the desired goals or aims of the program.

Quality improvement is a method that formalizes the way teams work. When a bottleneck or gap is apparent in clinic operations, a solution is applied to fix it. Using quality improvement activities, the team collects small amounts of data to measure change and ensure that modifications implemented by the team are having the intended effect.

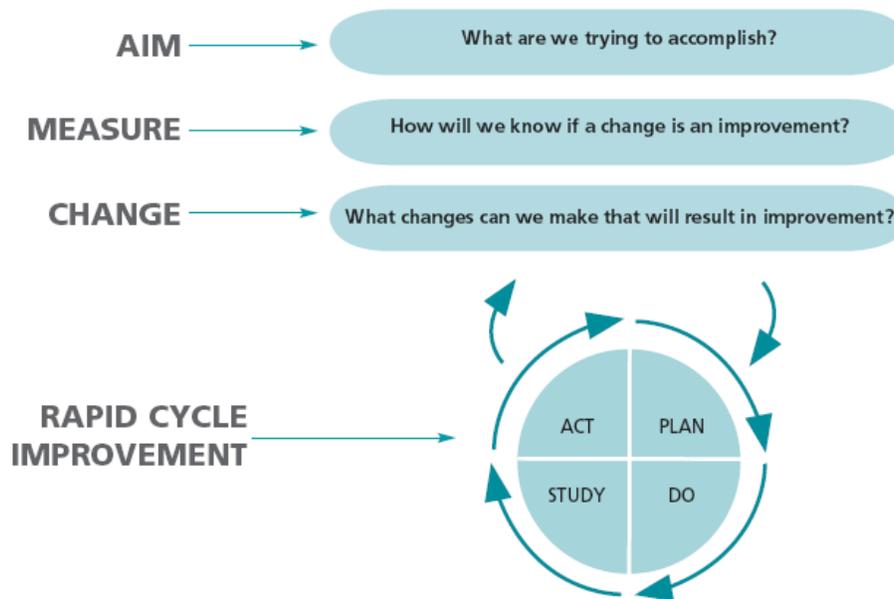
Team Engagement

Importantly, quality improvement is a method that implementation teams can use to engage stakeholders to participate in the process. The teams are empowered to identify problems or flaws in system design that lead to poor quality. Teams can try out different ideas to improve how care is delivered in multiple, brief, small experiments of change. The teams conduct frequent, targeted quality measurement in a way that gives them instant feedback on whether the changes help move the team toward their goal or not.

The Model for Improvement

In this section we outline the Model for Improvement (Langley et al., 2009). There are, however, many different models for quality improvement and “no one strategy is superior than another based on effectiveness, ease of implementation or cost.” (Powell et al., 2009)

The Model for Improvement (Langley et al., 2009)



The Model for Improvement has two basic components: the first addresses three fundamental questions and the second is the rapid cycle improvement process. In the first component of the model, the implementation team asks about the aim, how to measure the improvement and what changes are required. The second component is a method of rapid cycle improvement. The overall model is designed to develop, test and implement changes.

Three Fundamental Questions

1. What are we trying to accomplish?

Setting the Aims: Improvements require clearly defined aims. Aims will help you stay on track throughout your improvement efforts. To facilitate the work of those implementing Navigation, the Cancer Journey Quality Improvement and Evaluation Framework articulates the aims for each component of the Navigation initiative.

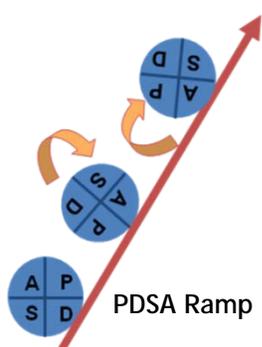
2. How will we know if a change is an improvement?

Establishing Measures: Measures assess whether the changes made are leading to tangible improvements. They provide concrete evidence to support the case for change.

3. What changes can we make that will result in improvement?

Testing Changes: All improvements require changes, but not all changes result in improvements. The implementation team will have ideas about the changes that need to be made and the changes that are most likely to result in improvement. Ideas for change can come from a variety of sources, such as team problem-solving, critical thinking and reflection, creative thinking, a hunch or an idea from the scientific literature. Once the change is identified, the next step is to test the change by using Rapid Cycle Improvement, or the PDSA (Plan-Do-Study-Act) cycle. The implementation team plans for the change, tries the change, observes the results and acts on what is learned. This is the method used for action-oriented learning.

Rapid Cycle Improvement



The second component of the quality improvement model is implementing a rapid cycle improvement process – the PDSA cycle. PDSA is a way to implement and assess change, and to keep the team and the project on track. PDSA cycles can be used to develop change ideas, test small-scale changes and implement changes to achieve aims.

Rapid cycle improvement works because processes have to change so that practices can change.

The time frame for testing small-scale changes is brief. Cycles should be conducted over a short time period, preferably no more than one to two weeks. Each change idea may require a series of PDSA cycles to test it. Any changes must be small and step-wise. The process of using a series of PDSA cycles to test an

idea is called a PDSA ramp. The team can implement PDSA ramps one after the other or simultaneously.

Below are the steps to follow to conduct a PDSA cycle:

- 1) *Gather your implementation team.* Discuss your progress to date and some of the current barriers or hurdles in your work. Select one of the most relevant problems or hurdles and identify the purpose of the action that is needed to address it. Does the team need to:
 - *Develop a change idea* (brainstorm to solve a problem or conduct rapid cycles to gather information and address a problem)? The team knows there is a problem but is not sure how to address it. Try a Defect Check Sheet or a Small Survey to isolate and identify the problem.
 - *Implement and test a change* (take the steps to make a change and make sure that it worked). The team knows what needs to happen next, so it designs a small-scale modification to implement systematically and measure to track the outcome. If the change appears to be successful, the change can be implemented on a larger and/or more complex scale.
- 2) *Use a PDSA Cycle worksheet* to plan the rapid cycle.
- 3) *Communicate results* early and often to all stakeholders.

Teams identify the change ideas and use a series of PDSA cycles to develop and test small changes on a small scale in different contexts.

PDSA Cycle Steps (Health Quality Ontario, 2012)

Step 1: Plan



State the purpose of the PDSA:

- Are you developing a change idea, testing a change or implementing change?
- What is your change idea?
- What indicator(s) of success will you measure?
- How will data on these indicators be collected?
- Who or what is the subject of the test?
- How many subjects will be included and over what time period?
- What do you hypothesize will happen and why?

Step 2: Do



- Conduct the test
- Document results, including problems and unintended consequences
- Collect and begin analysis of the data

Step 3: Study



- Complete analysis of the data and study the results
- Compare the data to your predictions
- Summarize and reflect on what was learned

Step 4: Act



- Refine the change idea based on lessons learned from the test
- Prepare a plan for the next test

Tips for Testing Change

- *Stay a cycle ahead.* When designing a test, imagine at the start what the subsequent test or two might be given the possible findings of the study phase of the PDSA cycle.
- *Scale down the scope of tests and keep measurements small and feasible.* Rather than testing the change on 100 patients, use a sample of 10 patients. The same idea applies to the location or duration of the test. Keep the time frame for the test small, to occur over one or two weeks rather than several months.
- *Pick willing volunteers.* Work with those who want to work with you.
- *Avoid the need for consensus, buy-in or political solutions.* Save these for later stages. When possible, choose changes that do not require long processes of approval, especially during the early testing phase.
- *Don't reinvent the wheel.* Instead, replicate changes made elsewhere.
- *Pick easy changes to try.* Look for the ideas that seem most feasible and will have the greatest impact.
- *Avoid technical slowdowns.* Don't wait for the new computer to arrive, try paper and pencil instead.
- *Reflect on the results of every change.* Most work systems leave too little time for reflection on work. The study phase of the cycle is crucial and is too often overlooked. After making a change, a team should ask:
 - What did we expect to happen?
 - What did happen?
 - Were there unintended consequences?
 - What was the best thing about this change? The worst?
 - What might we do next?

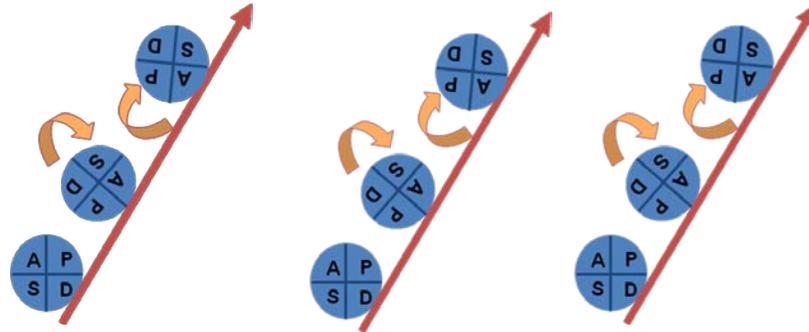
Too often, people avoid reflecting on failure. Remember that teams often learn very important lessons from failed tests of change.

- *Be prepared to end the test of a change.* If the test shows that a change is not leading to improvement, the test should be stopped. Note: Failed tests of change are a natural part of the improvement process. If a team experiences very few failed tests of change, it is probably not pushing the boundaries of innovation.
- *Collaboration among different departments and across professions* is essential to achieving systemic change.

Linking Tests of Changes

Testing changes is an iterative process: the completion of each test rolls directly into the start of the next test. A team learns from the test (What worked and what didn't work? What should be kept, changed or abandoned?) and uses this knowledge to plan the next test. As the cycles continue, the tests increase in complexity, scope and application. The team continues linking tests in this way, refining the change until it is ready for broader implementation and ultimately achievement of the aim. Remember that a team can implement PDSA ramps one after the other or simultaneously (see the figure following).

Simultaneous PDSA Ramps



Online QI Resources and Tools

- [The Institute for Healthcare Improvement](#)
Resources and tools can be accessed free of charge once a login and password are acquired.
- [The Health Quality Ontario QI Guide](#)

Communicating and Disseminating Results

The findings from rapid cycle improvements can be used to promote the gains and successes of the new program to all stakeholders and can contribute to the key messaging of the project. Use as many existing channels of communication as possible to communicate these successes and advances in implementation (e.g., newsletters and websites). Tailor the format and content of communications to intended audiences (e.g., brief emails to management and updates in volunteer newsletters). Finally, ensure that the program leads, champions and facilitators are informed of quality improvement and evaluation activities so that this information is conveyed through all channels of communication.

Sustainability

This section considers ways to build organizational capacity to support Navigation. Key concepts are the notions of sustainability and embeddedness. The activities of implementation serve to embed Navigation into the everyday workings of an organization.

The [NHS Sustainability Guide](#) is a diagnostic tool that is used to predict the likelihood of the sustainability of your change project. This sustainability guide provides practical advice on how you might increase the likelihood of sustainability for your improvement initiative.

NHS, 2010

Virani, Lemieux-Charles, Davis et al. (2009) discuss “organizational memory,” which refers to the storage or embodiment of knowledge in various “reservoirs” within the institution. It can be thought of as the ability of an organization to sustain new initia-

tives, institutionalize the initiatives in standard operating procedures and to make them a permanent component of the practice environment (make them routine).

Knowledge reservoirs are mechanisms that serve to retain knowledge within the practice environment's memory. Examples of knowledge reservoirs include individuals with expertise (people), standard screening processes (routines), policy and procedure documents (artifacts), one person prompting another (relationships), bulletin boards (information space), water cooler conversations (culture) and formal role expectations (structure). (Virani, 2009)

In the implementation of pain management guidelines in neonatal care across Canada, Stevens, Lee, Law et al. (2007) established the following four levels where barriers to implementation and knowledge translation exist:

- **Individual:** behaviour, attitudes and beliefs, previous knowledge and experiences
- **System:** organizational priorities, institution-wide policies, guidelines and procedures
- **Unit:** culture and context, unit leadership, evaluation methods, staffing issues
- **All levels:** time and workload, resources, buy-in

The categorization of barriers is helpful because management teams must consider how strategies to implement and embed Navigation must be targeted to all levels in the organization.

Embed Navigation in:

- Staff and volunteer position descriptions
- Staff and volunteer orientation, training and professional development
- Institutional policies, procedures and quality metrics
- Institutional websites and newsletters
- Staff performance metrics and reviews
- Research activities
- Institutional performance indicators
- Patient education initiatives
- Patients' expectations as a standard of care

Chapter 7: Tools and Resources

Cancer Journey Toolkit

(most resources available in English and French)

To find these materials, access www.cancerview.ca, choose the “Treatment & Support” menu and then “Person-Centred Toolkit and Resources” under “Supportive Care” in the list down the left of the screen.

- Guide to Screening for Distress, The 6th Vital Sign
- Advances in Survivorship Care: Resources, Lessons Learned and Promising Practices
- Pan-Canadian Adult Assessment Guideline
- Pan-Canadian Symptom Management Guidelines
- Pan-Canadian Guidance on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors
- Manage Cancer-Related Fatigue: For People Affected by Cancer
- Co-stars (protocols of Pan-Canadian Guidelines for telephone/internet use)
- Volunteer Learning Kit
- Diversity Kit
- The Knowledge Exchange – Decision Support (KE-DS) Toolkit
- Psychosocial education resources and tools
- Guide to Navigation (first edition), 2010

Other Resources for Navigators

- CAPO Standards of Psychosocial Health Services for People with Cancer and Their Families www.capo.ca/pdf/CAPOstandards.pdf

Navigation Education

| Education and Training for Professional Navigation | Format | Web site |
|---|--|---|
| Alberta Health Services Cancer Patient Navigation Course for Professionals (cost associated) | Nine-module course on CD, with moderator | ACB.ondec@albertahealthservices.ca |
| deSouza Institute Patient Navigation Course (free to nurses in cancer care in Ontario) | One-day workshop and online modules | http://desouzanurse.ca/courses/patient-navigation-05-credits |
| Interprofessional Online Distance Education (IPODE) Screening for Distress Education Program (free) | 6-hour online module | http://www.ipode.ca/ |

Navigation Program Tools

These documents, which pertain to professional Navigation, are available in the Cancer Journey Action Group [Guide to Navigation](#) (2010), courtesy of Cancer Care Nova Scotia:

- Navigational Process Chart
- Navigation Referral Follow-up Letter
- Patient Care Profile
- Triage Assessment Tool
- Referral Form
- Cancer Patient Navigation Data Log
- Patient/Family Education Log
- Practical Needs Profile

Websites for Navigators, Patients and Families

- BC Cancer Agency www.bccancer.ca
- Brain Tumour Foundation of Canada www.braintumour.ca
- Canadian Association of Psychosocial Oncology www.capo.ca
- Canadian Breast Cancer Foundation www.cbcf.org
- Canadian Cancer Society www.cancer.ca
- CancerCare www.cancercare.org
- Canadian Virtual Hospice www.virtualhospice.ca
- CancerviewCanada www.cancerview.ca
- Carcinoid Endocrine Tumour Society Canada www.cnetscanada.org

- Colorectal Cancer Association of Canada www.colorectal-cancer.ca
- Kidney Cancer Canada www.kidneycancercanada.org
- Lung Cancer Canada www.lungcancercanada.ca
- Myeloma Canada www.myelomacanada.ca
- Ovarian Cancer Canada www.ovariancanada.org
- Prostate Cancer Canada www.prostatecancer.ca
- Smoking Cessation: Canadian Cancer Society
Smokers Helpline 1-877-513-5333 www.cancer.ca
- Thyroid Cancer Canada www.thyroidcancercanada.org
- Speak Up: End-of-life care and Living Wills www.advancecareplanning.ca
- Young Adult Cancer Canada www.youngadultcancer.ca

Support Groups/ Programs for Navigators, Patients and Families

- CancerChatCanada
<http://cancerchatcanada.ca/>
- Cancer Transitions
<http://www.bccancer.bc.ca/RS/VancouverIslandCentre/sprograms.htm>
- Empower
<http://www.bccancer.bc.ca/RS/VancouverIslandCentre/sprograms.htm>

Recommended YouTube Channels

- Brain Tumour Foundation of Canada www.youtube.com/user/braintumourfdn
- Canadian Breast Cancer Foundation
..... www.youtube.com/user/CBCFAtlanticRegion
- Canadian Virtual Hospice www.youtube.com/user/cvhcvfsp
- Cancer View Canada www.youtube.com/user/cancerview
- Ovarian Cancer Canada www.youtube.com/user/OvarianCancerCanada

Multilingual Resources

- Canadian Cancer Society www.cancer.ca
- Cancer Care Manitoba www.cancercare.mb.ca
- Vancouver Coastal Health www.vch.eduhealth.ca

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Appendix A: Navigation Grid (Cancer Journey Action Group, 2010)

| <p>General Definition of Function Navigation is a proactive, intentional process of collaborating with a person and his or her family to provide guidance as they negotiate the maze of treatments, services and potential barriers throughout the cancer journey.</p> | | |
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| <p>Vision for Cancer Patient Navigation Cancer Patient Navigation is part of an integrated system of cancer service delivery. Navigators work with the patient and family and their interdisciplinary team to assess needs, provide supportive care, answer questions, identify and address any barriers to quality care, and facilitate access to needed resources and services. Navigation aims to improve both coordination in services and continuity throughout cancer care, as well as quality of life for the patient and family throughout the cancer journey.</p> | | |
| <p>Overarching Goal of Navigation Programs Navigation programs aim to improve a person’s cancer journey by:</p> <ul style="list-style-type: none"> • increasing capacity for knowledge and support • increasing capacity to meet identified needs • reducing anxiety • overcoming barriers and increasing capacity to access clinical and psychosocial services • improving coordination among individual services at various points and ensuring continuity across all services | | |
| Role Descriptions | Professional Navigator | Peer/Lay Navigator |
| <p>Characteristics</p> | <ul style="list-style-type: none"> • is a health professional with specialized knowledge of oncology • is part of an interprofessional team; provides an effective clinical function • performs formal, standardized clinical assessment and intervention • provides person-centred care; ensures care team is aware of need for and meaning of a person-centred approach • creates and follows a care plan at certain points or throughout cancer journey in consultation with team and person/family • is familiar with and collaborates with peer/lay navigators where applicable • engages in a pro-active, intentional process • coordinates care and services • actively monitors care at certain points or throughout cancer journey | <ul style="list-style-type: none"> • is a trained peer/lay person, sometimes paid • is often a person with a cancer experience • provides person-centred care • provides general information about cancer journey • focuses on support, empowerment and self-care for patient • is familiar with and collaborates with professional navigators where applicable • engages in a proactive, intentional process • acts in response to concerns identified by patient and family within scope of role • provides links or facilitates referrals to community agencies and service providers • may facilitate referrals to health care professionals as needed and within scope of role • provides emotional support and/or shares personal experience within role guidelines |

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| | | <ul style="list-style-type: none"> • intervenes within scope of practice on patient’s and family’s behalf • establishes linkages and coordinates care among agencies and service providers • provides direct referrals, as desired by patient or family, to other professionals and services • provides education about disease and related issues and self-care • provides emotional support during cancer journey • works with patient, family and community to facilitate transitions • provides information, support and guidance in decision-making • has access to medical records • maintains record of navigation in accordance with institutional standards and privacy legislation | <ul style="list-style-type: none"> • supports communication with health care providers • may intervene at certain points or throughout the cancer journey • may advocate for patient through health care team within role guidelines • assists with record-keeping in accordance with patient and/or organizational requirements and privacy legislation |
| Services Provided in Seven Supportive Care Domains | 1. Informational | Information and advice about disease, process of treatment, side-effects, services, quality of life, adaptation and changes in ability; instruction in self-management; assistance in decision-making | Information about self-management, tips, services; information about cancer journey process; peer/lay perspective on experience of cancer; support decision-making; encouragement to seek help from professionals and community organizations |
| | 2. Psychological | Comprehensive assessment; professional intervention based on standards of practice; facilitated referral as needed | Identification of concerns, response, validation; peer/lay perspective on experience; offer of hope; encouragement to seek help from professionals and community organizations; referral to resources |
| | 3. Emotional | Comprehensive assessment; professional intervention based on standards of practice; facilitated referral as needed; support in dealing with family’s reactions; support for patient and family to express needs to care team; identification of and building on patient’s and family’s strengths | Identification of concerns, response, validation; peer/lay perspective on experience; normalization of experience; encouragement to seek help from professionals and community organizations |
| | 4. Spiritual | Comprehensive assessment; professional intervention based on standards of practice; facilitated referral as needed | Identification of concerns, response, validation; peer/lay perspective on experience; encouragement to seek help from professionals and community organizations |

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| | 5. Physical | Comprehensive assessment; specific professional interventions and facilitated referral as needed; follow-up on interventions used; consideration of medical history; information about possible symptoms, symptom and pain management; medication changes; decreased fragmentation across care team throughout the continuum of care | Identification of concerns, response, validation; peer/lay perspective on experience; encouragement to seek help from professionals for medical concerns |
| | 6. Social | Comprehensive assessment; professional intervention based on standards of practice; facilitated referral as needed; provides broad perspective to care team about specific patient and family situation | Identification of concerns, response, validation; peer/lay perspective on experience; encouragement to seek help from professionals and community organizations |
| | 7. Practical | Comprehensive assessment; professional intervention based on standards of practice; facilitated referral as needed | Identification of concerns, response; validate; offer peer/lay perspective on experience; encouragement to seek help from professionals and community organizations; some direct services (e.g., filling out forms, connecting to transportation, translation) |
| Scope of Practice in Key Areas | Assessing needs and existing resources/strengths | Provides systematic screening/triage and comprehensive clinical assessment for patients and families using standardized, evidence-based tools | Within scope of role, identifies needs and responds to concerns identified by patient and family |
| | Education | Offers standard and personalized medical and psychosocial information and explanation for patient and family, throughout the continuum of care, based on expert knowledge/skill set in oncology | Provides information about patient experience; identifies expected events and related concerns; provides basic health care information |
| | Access | Provides direct referrals to other professionals and services as required following clinical assessment | Encourages help-seeking from professionals; may facilitate referrals to professionals in some cases, according to defined scope of role; provides contacts for practical and support services |
| | Support | Provides emotional/psychological support; aids with decision-making based on expert clinical knowledge; focuses on empowerment, building on patient's and family's strengths and resources | Provides emotional support based on extensive peer/lay support training and/or experience; supports patient decision-making; helps to empower the person |

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| | Coordination | Designs care plan within scope of discipline, participates in interdisciplinary care plan, coordinates care across settings, sets up appointments, explains upcoming appointments/procedures, helps to integrate services; is central point of contact and communication with all health care team members and service providers throughout the continuum of care; is a direct link to tumour board networks; has access to and can share medical records; monitors and evaluates plan of care | Links patient to community resources; encourages help-seeking from professionals; may facilitate referrals to health care professionals as needed and within scope of role |
| | Brokering | Actively negotiates for service delivery to clients with the range of professionals and administrators | |
| | Advocacy | Advocates directly for patient with care providers and services, intervenes regarding problems or barriers, advocates for system changes when gaps and inefficiencies are identified | Encourages self-advocacy, empowerment of person |
| | Documentation | Maintains detailed clinical records, integrates with medical file, monitors care according to professional and institutional standards | Records patient information in some cases, according to defined scope of role and agency expectations |
| | System-level change | May identify system barriers (gaps in services, problems with procedures or policies) in the course of daily interactions with patients, and intervene to address/improve them in consultation with interprofessional team and/or administration; may perform patient advocacy and co-ordination across services and professionals, improving care systems | May identify gaps in services, problems with procedures or policies in the course of daily interactions with patients, and communicate concerns to appropriate person in the organization |
| | Leadership/ Team building | Provides leadership and influences clinical standard-setting, policy development and change management; promotes and facilitates an interdisciplinary team approach to delivery of care and decision-making; provides leadership in the coordination and implementation of quality improvement activities; facilitates the development and implementation of care pathways | May act as representative on a team, helping to create programs to address identified gaps; offers peer/lay-based leadership and support to other volunteers or participates in mentoring |

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| <p>Skills and training</p> | <ul style="list-style-type: none"> • Health professional - often a nurse or a social worker • Extensive clinical knowledge of oncology and/or sub-specialty in specific cancer site • Specialized training in navigation process and best practices • Ability to network and coordinate care among all resources, services and professionals • Interpersonal communication and listening skills • Empathy and sensitivity • Knowledge of psychosocial issues, specific needs, possible barriers to care for diverse populations (e.g., cultural, racial, sexual, religious) • Expert in family dynamics • Conflict resolution skills • Awareness of provincial and community cancer agencies, services and resources • Ability to work autonomously • Training in telepractice | <ul style="list-style-type: none"> • Knowledge of volunteer role and boundaries • Training in navigation process and best practices at peer/lay level • Interpersonal communication and listening skills • Empathy and sensitivity • Ability to maintain client confidentiality and privacy • Knowledge of conflict resolution and incident reporting process • Awareness of limits to knowledge-sharing and when to refer • Knowledge of psychosocial issues, needs, possible barriers to care for diverse populations (e.g., cultural, racial, sexual, religious) • Awareness of provincial and community cancer agencies, services and resources • Professional language translation skills in some cases; ability to access translation services |
| <p>Expected Outcomes</p> | <ul style="list-style-type: none"> • The cancer experience is improved for the person and family; all are: <ul style="list-style-type: none"> - well informed - prepared with a tailored care plan, with navigator as focal point of contact - supported and guided - empowered to make treatment-related decisions - better equipped to manage anxiety and distress • Barriers to care are identified and addressed; gaps across care path are improved • Disparities are reduced for marginalized groups • Transition points are well managed • Care is timely • Care is appropriate to identified needs (medical, nursing, psychosocial, supportive and palliative) • Service provision is continuous and coordinated • Care team communicates and collaborates well • Service duplication is reduced • Identification of system-related problems is improved | <ul style="list-style-type: none"> • The person and family are: <ul style="list-style-type: none"> - better informed - supported and guided - empowered to make decisions about non-medical issues - better able to manage anxiety and distress - empowered to communicate better with health care providers, family and others • Barriers are identified and addressed, within scope of program • Disparities are reduced for marginalized groups • Services are more accessible and better coordinated, within scope of program |

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| Possible Modalities | <ul style="list-style-type: none"> • Face-to-face meetings • Telephone consultation (telemedicine, telepractice) • Online communication (email, chat rooms, online support groups) • Referrals to web-based information (websites, databases) • Referrals to other information sources (resource centres, health libraries, articles, books) |
| Possible Locations | <ul style="list-style-type: none"> • Clinic/hospital: outpatient or inpatient • Community organization • Home • Online |
| Resource Requirements | <ul style="list-style-type: none"> • Compensation (for professionals/clinicians; for peer/lay navigators in some cases) • Extensive training curricula, targeted to specific roles and institutional demands • Patient education/information materials • Information about and links to provincial and local resources • Instructors/supervisors • Curriculum developers • Mechanisms to support navigators in work, to debrief and to alleviate emotional stress (e.g., mentoring, professional networks, communities of practice) • Institutional space/office supplies/technical support • Program administration and management • Monitoring and evaluation of programs and individual practice |
| Critical Success Factors | <ul style="list-style-type: none"> • Leadership • Participation • Problem assessment/problem solving • Organizational structures/processes (e.g., best practice guidelines, accountability framework) • Resource mobilization; referral pathways and links • Communications plan; marketing of program • Right people with the right skillsets • Program management/coordination • Program evaluation mechanisms |

Appendix B: Cancer Journey Navigation Program Logic Model

| Components | Planning & Assessment | Staff Selection, Training & Support | Teamwork & Collaboration |
|-----------------------|--|--|--|
| Inputs | <ul style="list-style-type: none"> Staffing | <ul style="list-style-type: none"> IS/IT | <ul style="list-style-type: none"> Facilities Materials/Documents |
| Activities | <p>Assessment of:</p> <ul style="list-style-type: none"> Problem or local situation Individual staff perceptions, motivation Existing social supports Organizational capacity for Navigation program Barriers to implementation Tailoring Navigation program to local context Creation of implementation plan | <ul style="list-style-type: none"> Select and recruit navigators Conduct education and training in: <ul style="list-style-type: none"> Person-centered approach Best practices Institutional Guidelines Evaluation and QI process | <ul style="list-style-type: none"> Develop capacities of navigators and other health care team members to work in an interprofessional team using best practices Develop and implement processes and protocols to promote team cooperation and communication |
| Outputs | <ul style="list-style-type: none"> Documentation of rationale for need for Navigation program Best practice guidelines for Navigation Implementation plan Barrier management strategy Tailored components of Navigation plan, including tools, methods, etc. | <ul style="list-style-type: none"> Person-centered educational modules for navigators and other staff Navigators hired and trained Training sessions for other staff | <ul style="list-style-type: none"> Interprofessional model of care for Navigation |
| Process Outcomes | <ul style="list-style-type: none"> Increased preparation and readiness for implementation of Navigation programs Overcoming the barriers for Navigation programs | <ul style="list-style-type: none"> Increased knowledge skills and capacity for navigation as part of cancer care process Increased awareness and integration of key attributes of person-centered care Increased knowledge about the core competencies required | <ul style="list-style-type: none"> Increased adherence to evidence-based guidelines for navigation Improved team collaboration and service coordination Provision of safe and accessible care Staff satisfaction with teamwork and collaboration |
| Short-Term Outcomes | <ul style="list-style-type: none"> Navigation program implemented as designed | <ul style="list-style-type: none"> Enhanced staff competencies and capacity for person-centered approach to navigation | <ul style="list-style-type: none"> Improved coordination, continuity and integration of cancer care delivery with navigation services Working toward person-centered care |
| Intermediate Outcomes | <ul style="list-style-type: none"> Increased patient and family satisfaction with the experience of care | <ul style="list-style-type: none"> Increased patient and family awareness of supportive care services and resources | <ul style="list-style-type: none"> Increased patient and family knowledge about self-management and self-care |
| Long-Term Outcomes | <ul style="list-style-type: none"> Sustainability of Navigation program | <ul style="list-style-type: none"> Reduced patient and family stress and increased quality of life | <ul style="list-style-type: none"> Reduced costs to cancer care system |

| Components | Organizational Capacity Building | Patient Engagement | Monitoring, Evaluation & Reporting | Dissemination |
|-----------------------|--|---|--|--|
| Inputs | <ul style="list-style-type: none"> Staffing | <ul style="list-style-type: none"> IS/IT | <ul style="list-style-type: none"> Facilities | <ul style="list-style-type: none"> Materials/Documents |
| Activities | <ul style="list-style-type: none"> Identify and promote champions and other positive social influences Develop policies and boundaries for navigation Secure skilled human and financial resources Develop intra-organizational communication mechanisms | <ul style="list-style-type: none"> Create and implement processes to ensure that patients and families that work with the navigator: <ul style="list-style-type: none"> Are informed about the navigator's function Are aware of the scope of the navigator's role Participate meaningfully in the navigation process and in evaluating the navigation program | <ul style="list-style-type: none"> Measurement development Tracking and progress reporting of patients informed about navigation function and availability, number of patients receiving navigation, etc. Barrier management Sharing results | <ul style="list-style-type: none"> Creation of mechanisms to share results and lessons learned about the practice of navigation with internal stakeholders Development of products to share lessons learned with external stakeholders Participation in conferences, collaborations, etc. |
| Outputs | <ul style="list-style-type: none"> Champions Policy documents Resource allocation documents | <ul style="list-style-type: none"> Patient information sessions and consultations Patient navigation | <ul style="list-style-type: none"> Data collection and reporting system Progress reports | <ul style="list-style-type: none"> Knowledge products Collaborations Conferences Publications and presentations |
| Process Outcomes | <ul style="list-style-type: none"> Improved infrastructure to support navigation program | <ul style="list-style-type: none"> Patients and families increasingly involved in all aspects of the navigation process | <ul style="list-style-type: none"> Continued implementation of QI and PDSA cycle | <ul style="list-style-type: none"> Internal and external stakeholders increasingly aware of existence of navigation programs |
| Short-Term Outcomes | <ul style="list-style-type: none"> Enhanced infrastructure that supports an integrated approach to navigation | <ul style="list-style-type: none"> Increased knowledge, awareness, involvement in, and understanding of the navigation process | <ul style="list-style-type: none"> Increased understanding of navigation effectiveness and necessary modifications at individual, team and organizational levels | <ul style="list-style-type: none"> Increased understanding of navigation program by internal and external stakeholders, including challenges and opportunities |
| Intermediate Outcomes | <ul style="list-style-type: none"> Increased patient and family satisfaction with the experience of care | <ul style="list-style-type: none"> Increased patient and family awareness of supportive care services and resources | <ul style="list-style-type: none"> Increased patient and family knowledge about self-management and self-care | |
| Long-Term Outcomes | <ul style="list-style-type: none"> Sustainability of navigation program | <ul style="list-style-type: none"> Reduced patient and family stress and increased quality of life | <ul style="list-style-type: none"> Reduced costs to cancer care system | |

(PricewaterhouseCoopers LLP, 2010a)

Appendix C: Guiding Principles for Knowledge Implementation

(PricewaterhouseCoopers LLP, 2010b)

Principle 1. Problem Assessment and Understanding: Early identification, supported by evidence (e.g., patient and staff testimonials, needs assessments, local data), and the subsequent introduction of knowledge can help alleviate a problem or issue.

Principle 2. Tailoring to Local Context: Innovations need to be tailored to suit the local situation, organizational characteristics, patient needs, etc. The goal is to have a planned and focused innovation that is suitable for the character and needs of the local context.

Principle 3. Assessment of Individual Perceptions and Motivations: It is important to assess the individual perceptions and motivations of the intended users of the knowledge. The assessment should include an examination of individual values, beliefs in credibility of the knowledge, behaviours toward sustaining the knowledge, beliefs about capabilities and confidence, emotional response to the knowledge, and the balance between competing options in order to make a decision about the behaviour.

Principle 4. Barrier Identification and Management: Barriers to using knowledge may include lack of understanding of the knowledge, poor attitudes toward using the knowledge, lack of skills for implementation and established habits. Those who want to bring about change must assess the local situation for potential barriers that may impede or limit uptake of the knowledge. These barriers must then be managed by targeting interventions to help minimize or remove them.

Principle 5. Identification of Social Influences: Social influences such as teamwork, champions and norms can affect people's behaviour when choosing whether or not to implement knowledge. Positive role models, opinion leaders and social supports can help to facilitate knowledge uptake. Negative social influences can hinder knowledge uptake and must therefore be recognized and addressed.

Principle 6. Training and Coaching: Individuals need to understand new knowledge and must learn when, where, how and with whom to use it. New skills will likely be required. Training and coaching helps individuals take up knowledge by enhancing their understanding and by helping them develop the necessary skills for implementation within their practice environment. Training and coaching also serve to reinforce uptake by providing advice, encouragement, practice opportunities and feedback.

Principle 7. Organizational Capacity Building and Infrastructure Development: For an innovation to be implemented, the organization must be ready for change and be able to support implementation of the innovation. Innovations must fit with an organization's strategic aims and culture, must be well supported by an infrastructure that

includes dedicated human resources and financial supports, and must be visibly supported by leaders in the organization.

Principle 8. Patient Engagement and Implementation: If an innovation is to improve the experience of patients and families, the implementation process must include them. The process must ensure that patients and families are informed about the innovation; are aware of the scope, role and expectations of themselves and their health care providers; and are given the opportunity to participate meaningfully in implementation and in evaluation and subsequent decision-making.

Principle 9. Monitoring, Evaluating, Reporting, Disseminating: Any innovation must have specific and measurable aims. Implementation and subsequent improvement must be tracked over time and the results and lessons learned shared with appropriate stakeholders. A process of continuous quality improvement should be adopted whereby measurements of quality are frequently conducted and quickly fed back to a team. This feedback must then lead to modifications that can be tried, tested and improved upon. Results and lessons learned from the implementation of an innovation must be shared with appropriate stakeholders within the organization in order to make informed policy and practice decisions. Results and lessons learned should also be shared with a wider audience interested in implementation research. This information can be shared via conferences, publications, presentations, formal networking initiatives and collaboration.

Appendix D: Self-Assessment of Change Management Skills

(London Borough of Lambeth, 2007)

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This tool will help individuals think about whether they have the range of skills needed to make good change agents. It will help them identify their areas of strength and those that need to be developed. It can help senior management think about who would make a good change agent. How to use the tool:

- As a checklist for individuals to consider what aspects of their skills they need to develop.
- As a basis for management discussion about who would make a good change agent.
- As a discussion tool: Allow approximately 20 minutes for people to complete the checklist and to identify their areas for attention. Focus discussion on areas where there is consensus that work is needed, not on individual responses to particular questions.

Interpersonal Skills Needed to Manage Change Effectively

| | Good | Ok | Needs work |
|--|------|----|------------|
| 1. I speak persuasively when addressing an audience (a good advocate) | | | |
| 2. I intervene and project myself successfully in meetings | | | |
| 3. I listen attentively to others | | | |
| 4. I respond positively to colleagues' points | | | |
| 5. I am able to be open and share my thoughts and feelings with colleagues | | | |
| 6. I am articulate when talking to colleagues | | | |
| 7. I can sustain an argument when talking in meetings | | | |
| 8. I am sensitive to and aware of my colleagues' personal needs | | | |
| 9. I can help colleagues find solutions to problems | | | |
| 10. I inspire confidence through enthusiasm | | | |
| 11. I am able to control my emotions when dealing with colleagues | | | |
| 12. I am capable of accepting advice | | | |
| 13. I am able to admit my weaknesses | | | |
| 14. I can accept group decisions with good grace | | | |
| 15. I am not patronizing or condescending | | | |
| 16. I am not afraid to confront my colleagues when necessary | | | |
| 17. I am assertive | | | |
| 18. I encourage colleagues to use their initiative | | | |
| 19. I avoid being over directive or bossy | | | |
| 20. I am capable of cheerful compromise | | | |
| 21. I am aware of the effect of body language on social interaction | | | |
| 22. I am able to raise my colleagues' self-esteem through praise | | | |
| 23. I am able to reflect critically on my own performance | | | |

| | Good | Ok | Needs work |
|--|------|----|------------|
| 24. I am able to gather data and evidence to evaluate my own performance | | | |
| 25. I am good at passing responsibility on to colleagues | | | |
| 26. I give colleagues room to try things out, even if it means mistakes are made | | | |
| 27. I look for and share examples of good practice and success | | | |
| 28. I am genuinely interested in colleagues' ideas and views | | | |
| 29. I continue to learn from my colleagues | | | |
| 30. I am able to stand back and not over-organize others | | | |
| 31. I am able to communicate optimism to colleagues in the face of difficulties | | | |
| 32. I am able to find out how colleagues feel | | | |
| 33. I provide constructive and well-focused feedback | | | |

When you have completed the above table, use the following table to assess what skill areas are particularly strong or weak for you. All change agents tend to have stronger and weaker skill areas. The weaker areas will lead to particular types of problem in managing change. You need to try to develop your skills in all the key areas below:

| Skill Areas | Strategies | Question # |
|--|---|----------------------------|
| Help Individuals | <ul style="list-style-type: none"> • Support • Reward • Feedback • Not blaming but helping without taking over (show trust) | 4, 9, 15, 26, 31, 33 |
| Communicate as you never have before | <ul style="list-style-type: none"> • Vision, goals and actions • Coalition building, advocacy and bargaining • Checking things out | 1, 2, 6, 7, 10, 17, 21 |
| Do not over-organize | <ul style="list-style-type: none"> • Reduce focus on details • Allow flexible implementation • Integrate colleague's ideas into the process of change | 12, 14, 18, 19, 25, 26, 30 |
| Dealing with conflict and differences | <ul style="list-style-type: none"> • Without getting over-emotional or personally involved (staying in adult behaviour). <ul style="list-style-type: none"> - Handling opposition well helps achieve active implementation | 11, 14, 16, 17, 20 |
| Building trust, confidence and self-esteem | <ul style="list-style-type: none"> • Provide genuine feedback • Listen to others' ideas • Focus on progress and examples of development rather than statistics, performance, indicators, etc. • Feedback on success | 4, 10, 14, 22, 27, 33 |
| Real interest in others | <ul style="list-style-type: none"> • Contrived collegiality does not work | 3, 8, 15, 29, 32 |
| Emotion is important | <ul style="list-style-type: none"> • Do not minimize expressions of feelings • Recognize that it is alright to not always be rational | 5, 8, 13, 32 |
| Self-awareness | <ul style="list-style-type: none"> • Be aware of your own challenges and performance | 12, 13, 23, 24 |

Appendix F: Readiness for Change Checklist Error! Bookmark not defined.

(London Borough of Lambeth, 2007)

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This tool can be used as an individual self-reflection tool, but it will be more useful if used with groups of staff. If used with groups of staff:

- Have each participant complete the tool individually (allow 10 minutes for completion).
- If you, as manager, think that the team/section/service has a long way to go for more change, pool the results anonymously by collecting them beforehand (in blank envelopes) or invite the group to record their responses on a master copy using a flipchart, so that people do not feel obliged to defend their own perception.
 - Put the emphasis on moving forward not on ascribing blame.
- If you, as manager, feel that the group will be comfortable sharing their perceptions openly, work through each row in turn, checking out different perceptions.
 - If you all opt for a particular column, how can you get to the next column to the left?
 - If you differ in your views, why is this?
 - What ideas do any group members have for moving toward the left (as represented on this tool)?

Please Circle the appropriate statement – one of the four columns in each row below.

| | | | | |
|---|--|--|-------------------------------|-------------------------------------|
| 1. In the past, new policies or systems introduced by management have been: | Seen as meeting employee needs | Not well understood | Greeted with some resistance | Vigorously resisted |
| 2. Employees may be best described as: | Innovative | Independent | Uncommitted so far | Conservative or resistant to change |
| 3. The implementation of Navigation and related changes in the organization is viewed as: | A success | Moderately successful | Having only peripheral impact | Not successful |
| 4. Expectations of what this change will lead to are: | Consistent throughout the organization | Consistent among senior management but less so otherwise | Not consistent | Unclear |

| | | | | |
|--|--|--|--|--|
| 5. What can people directly affected by the changes tell you about the Navigation implementation plan: | A full description | A description of where it affects their own department or activity | A general idea | Nothing |
| 6. Intended outcomes of the change have been: | Specified in detail | Outlined in general terms | Poorly defined | Not defined |
| 7. Work procedures following the introduction of Navigation are seen as needing: | Major change | Significant alteration | Minor improvement | No change |
| 8. The problems addressed through Navigation were first raised by: | The staff directly involved | Managers | Outside bodies: CPAC, provincial cancer organizations | The change is not seen as addressing important and relevant service problems |
| 9. The next stage of change is viewed by staff as: | Crucial to the organization's future | Generally beneficial to the organization | Beneficial only to part of the organization | Unimportant |
| 10. Top management support for Navigation is: | Enthusiastic | Limited | Minimal | Unclear |
| 11. The management team has: | Committed significant resources to the changes | Assigned token additional resources to the changes | Expects the change to be implemented from existing resources | Not planned the resources that are needed |
| 12. The management performance appraisal and review process is: | An important part of management development | A helpful problem-solving process | Routine | An obstacle to improvement |
| 13. The change deals with issues of relevance to the practice environment: | Directly | Partly | Only indirectly | Not at all |
| 14. Navigation and related changes: | Make jobs more rewarding | Make jobs easier and more satisfying | Have little impact on people's work | Make jobs harder |
| 15. Navigation and related change is technically: | Similar to others already underway | Similar to others undertaken in the recent past | Novel | Technically unclear |

Readiness for Change Checklist: Some Problems and Solutions

Track Record of Changes (Questions 1-3)

The potential problems are:

- Past changes have met with resistance
- Past changes were poorly understood
- Employees are thought to be too cautious
- Recently introduced changes have had limited or little success

The solutions are:

- Keep everyone informed by making information available, explaining plans clearly and allowing access to management for questions and clarification.
- Ensure that change is solid realistically by making a practical case for it. Explain change in terms which the employee will see as relevant and acceptable. Show how change fits service needs and plans. Spend time and effort on presentations.
- Prepare carefully by making a full organizational diagnosis by spending time with people and groups, and building trust, understanding and support.
- Start small and build up a successful track record. Implement changes in clear phases.
- Plan for success by starting with things that can give a quick and positive pay-off. Publicise early successes. Provide positive feedback to those involved in successes.

Expectations of Change (Questions 4-6)

The potential problems are:

- Different people hold different ideas about the change
- People do not know what to expect
- Objectives are not clearly defined

The solutions are:

- Clarify benefits of changes by emphasising benefits to those involved, that is, to the service.
- Choose messages and messengers carefully and communicate often.
- Reinforce that the guidelines are evidence-based and that much of the value of the guideline pertains to improving patient and family experience with cancer (i.e., every patient will be screened and assessed for distress and all interventions will lead to the best possible outcome).

- Confirm that the initiative is being adopted as a standard around the country and is not a “cookbook” standardization project.
- Minimize surprises by specifying all assumptions about the change. Focus on outcomes. Identify potential problems.
- Communicate plans by being specific in terms that are familiar to the different groups of employees. Communicate periodically and through various media. Ask for feedback. Do not suppress negative views; listen to them carefully and deal with them openly.

Who ‘Owns’ the Problem or the Idea for Change? (Questions 7-9)

The potential problems are:

- The procedures, systems, sections and services involved are seen to be a problem.
- The change was planned or introduced by top management or staff sections.
- The change is viewed as purely a matter of procedure.

The solutions are:

- Specify plans in terms that people understand. Ensure that employees’ problems are addressed explicitly as part of the change. Arrange for visible outcomes
- Clarify employees’ views by exploring their concerns about the changes and examining the impact on the day-to-day routines.
- Present a clear case by specifying who wants change and why. Explain longer-term advantages. Identify common benefits. Present potential problems clearly. Listen to problems.

Top Management Support (Questions 10-12)

The potential problems are:

- Concerns or doubts about top management support for the change.
- Whether top management will provide resources.
- The current management performance appraisal process is seen to be an obstacle to change.

The solutions are:

- Build a power base by becoming the expert in the problems involved. Understand top management concerns. Develop informational and formal support. Develop a strong and polished presentation in top management language.
- Develop clear objectives and plans by establishing a clear timetable. Set up review processes to be supportive. Bring top and middle management into the review process. Focus meetings on specific outcomes and specific problems.

Acceptability of Change (Questions 13-15)

The potential problems are:

- The planned change conflicts with or does not with fit other plans.
- There a little or no clear sense of direction.
- The proposed changes are perceived to place greater demands on people.
- The change is perceived to involve new technology products/services and expertise.

The solutions are:

- Identify relevance of change to plans by reviewing plans and specifying how change fits. Incorporate changes into on-going developments. If possible, frame changes in terms of the organization's style.
- Clarify plans for changes by communicating simply and openly.
- Implement with flexible or adaptable people, and people familiar with some or all of the change, in a part of the service where there are strong supporters for change. Recognize why people support change (career, rewards, organizational politics).
- Do not oversell the change by being adamant about conflicts with present practices. Encourage discussion of these conflicts.

Appendix G: Identifying Barriers

Talk to Key Individuals (NICE, 2007)

Key individuals have specific understanding of a given situation and have the knowledge, skills and authority to enable them to think around a topic and explore new ideas. You may want to consider talking to a group of key individuals through one of their regular meetings, for example, a staff meeting.

Advantages:

- It enables ideas to be explored in an iterative fashion
- Detailed information can be obtained
- It is quick and inexpensive.

Disadvantages:

- It relies heavily on the key individual(s)
- The responses may be subject to bias
- It may be difficult to find the right person (or people) to talk to
- Additional corroboration may be needed.

Observe Clinical Practice in Action (NICE, 2007)

Sometimes the best way of assessing current clinical practice is by observing individual behaviours and interactions. This is especially appropriate if you are looking at events that happen quite often.

Advantages:

- It enables detailed analysis of current behaviours in a specific context
- It eliminates reporting bias
- It can provide a useful method for monitoring progress, if repeated on a regular basis

Disadvantages:

- It can be difficult to gain consent from the people you want to observe
- Peoples' behaviour can alter when they know they are being watched
- A skilled observer is needed to minimise influence on the person being observed
- Methods of data collection need careful consideration

A more formal way of doing this is through an audit.

Use a Questionnaire (NICE, 2007)

A questionnaire is a good way of exploring the knowledge, beliefs, attitudes and behaviour of a group of geographically dispersed healthcare professionals. Careful thought needs to be given to the design of the questions, as the quality of the answers relies heavily on the quality of the questions. Both electronic and paper formats can be used to encourage responses.

Advantages:

- It allows rapid collection of relatively large amounts of data from a large number of people
- It enables statistical analysis of standardized data
- It provides the opportunity to highlight the need for change through communication of the results
- It is relatively inexpensive.

Disadvantages:

- Significant time is needed to develop good questions
- It is not possible to ask follow-up questions
- The response rate may be poor and may be biased towards high performers
- The nature of self-reporting means it can be inaccurate.

Brainstorm (NICE, 2007)

Brainstorming is a way of developing creative solutions to problems. It can be done informally in small groups or as part of a focus group. The session starts with an outline of the problem and then participants are encouraged to come up with as many ideas as possible to solve it. One of the great things about brainstorming is that participants can bounce ideas off each other and develop and refine them further.

Advantages:

- It is fast and easy to do
- It generates lots of ideas
- It helps engage people in the process of change

Disadvantages:

- It needs a skilled facilitator
- More vocal members of the group may dominate the discussion
- Organising a session among a group of healthcare professionals can be difficult because of their clinical commitments

Provides free online training in brainstorming including the rules of brainstorming and running a brainstorming session.

Run a Focus Group (NICE, 2007)

Focus groups are a powerful means of evaluating current practice and testing new ideas. They comprise a facilitated discussion or interview involving a group of 6-10 people. Open questions are posed by the facilitator, who then encourages the group to discuss their experiences and thoughts, and reflect on the views of others.

Advantages:

- It enables a representative group of people to share ideas
- It allows a wide range of in-depth information to be obtained
- It encourages new ideas and perspectives
- It helps get people engaged in the change process
- It is relatively quick and easy to perform

Disadvantages:

- A skilled facilitator is needed to ensure everyone is able to express their views
- It can be difficult to find a suitable time for everyone to attend
- Incentives may need to be offered to encourage attendance
- Analysis can be time consuming
- Careful planning and analysis are needed

Case Studies (NCIS, 2006)

Case studies are useful when very detailed information about a past event may shed light on existing barriers.

Advantages:

- Can provide very detailed information about an issue or event
- Can gain insights when combined with other techniques

Disadvantages:

- Multiple forms of data collection and analysis are required
- Input from a variety of experts may be needed
- Can be time consuming and expensive
- Findings are open to subjective interpretation
- Findings from one case study may not be readily generalizable to other groups

Interviews (NCIS, 2006)

A face-to-face discussion with individual participants who are asked specific questions by an interviewer. The Interviews can be unstructured, semi- structured or structured.

Advantages:

- Detailed, in-depth information can be obtained
- Participants can express their own views
- Complex or unanticipated issues can be explored

Disadvantages:

- Time consuming and expensive
- The interviewer may introduce bias in terms of how the questions are asked or recorded
- Some participants responses may be inhibited
- Summarizing and comparing responses to open ended questions can be difficult

Surveys (NCIS, 2006)

A survey is a standardized set of questions assessing participants' knowledge, attitudes and/or self-reported behaviour. The questions can be open ended allowing participants to report their responses verbatim, closed, where participants have to select answers from a predetermined list, or a combination of both.

Advantages:

- They can be sent to healthcare professionals or patients anywhere in the country.
- Data can be collected from a large number of people in a relatively short period of time
- Respondents can complete the survey at their convenience
- Respondents can remain anonymous
- Relative inexpensive

Disadvantages:

- Considerable time may be needed for development and pilot testing
- It is not possible to ask follow-up questions
- Individuals may not accurately report their behaviour or the factors influencing their practice
- Response rate may be low

Nominal Group Technique (NCIS, 2006)

Nominal Group Technique is a highly structured discussion among a group of people whose ideas are pooled and prioritized.

Advantages:

- Many ideas can be generated in a short period of time
- All participants have input
- Fast and easy to execute
- Can be used to seek group consensus regarding prioritization of ideas

Disadvantages:

- Requires a highly skilled moderator
- Incentives are needed for people to attend
- Only a single issue or topic can be explored

Delphi Technique (NCIS, 2006)

The Delphi Technique is an iterative process in which information is collected from the same group of participants through a series of surveys.

Advantages:

- Participants remain anonymous
- Surveys can be sent out

Disadvantages:

- Considerable time is needed for question development, analysis and revision
- Participants may not be willing to fill out multiple surveys
- Response rate may be low

Arts Based Techniques (Kontos and Poland, 2009)

Arts based approaches offer the potential to foster critical awareness, to facilitate understanding and nurture sympathy. Dramatic performances have been successful in helping health care professionals reflect on the care they provide and increase their understanding of patient care issues (Shapiro and Hunt, 2003; Gray et al., 2003; Rosenbaum et al., 2005). Another technique is Improvisational theatre, where a short play is performed, followed by an identical presentation in which audience members are encouraged to physically replace the main character when they feel inspired to enact an alternative approach that might result in a more favourable outcome. This can foster critical thinking about the lived reality of the participants, the root causes and solutions to social problems, and change.

Appendix H: Professional Navigation Conceptual Framework

Reprinted from *Guide to Navigation*, Cancer Journey Action Group (2010)

| Dimension | Concepts | Process/Functions | Outcomes |
|---|--|---|--|
| <p style="text-align: center;">FACILITATING Continuity of care (experience of care as coherent and connected) (Organizational functions of the role) (Dimension health-system-oriented)</p> | <p>Information continuity <i>Use of information, disease or person focused, to make current care appropriate for each individual. Information is relevant to link care from one provider to another and from one healthcare event to another.</i> (Haggerty et al., 2003)</p> | <ul style="list-style-type: none"> • Having access to, and understand, high level of information on the cancer patients and their care • Providing timely and tailored information and advice to the interdisciplinary team and cancer patients (patient centered information) • Working closely with the interdisciplinary team to improve continuity of the information and knowledge of family/patients' needs and changes • Using communication tools and strategies to increase continuity of information | <ul style="list-style-type: none"> • Effectiveness in which coherent information is transferred and understood (<i>information on medical condition, patient's preferences, values, and context</i>): <ul style="list-style-type: none"> - among providers (e.g., SECON) - between institution (discharge plans, transfer of discharge information, referral data inventory) - between primary and specialty care (referral documents) (e.g., PCAT) - from patient perception (e.g., PCCQ; Experienced continuity) ✓ Accumulated knowledge: patients can be asked if they know their providers at earlier steps of the care trajectory; how well they know their providers, or providers can be asked how well they know their patient ✓ Satisfaction about information exchange in the team (e.g., EORTC-SAT32) |
| | <p>Management continuity <i>A consistent and coherent approach to the management of cancer that is responsive to a patient's changing needs. Providing a sense of predictability and security in future care for both patients and providers.</i> (Haggerty et al., 2003)</p> | <ul style="list-style-type: none"> • Conducting comprehensive screening and needs assessment (initial and ongoing) • Matching unmet needs with services, resources available and support systems within the cancer care organization and the community • Identifying lack of resources, finding temporary solutions and reporting the system gaps • Mapping continuum of care; explaining care plan; minimizing uncertainty (patient orientation); decreasing barriers to cancer care adherence • Referring and communicating with hospital and community teams • Doing prompt liaison • Facilitating coordination and organization of medical/psychosocial care (using care pathways) • Contributing to the elaboration and application of the interdisciplinary care plan • Facilitating interprofessional collaboration (hospital and community settings) | <ul style="list-style-type: none"> • Coherent and timely coordination of services (<i>shared care plan+ facilitate access to a broad range of services</i>) ✓ Longitudinal follow-up- completion rates of recommended treatment for cancer specific diseases or for "gaps" in care for chronic diseases (especially in transition) ✓ Perception of continuity of care (e.g., PCCQ; Experience continuity) • Participation of patient in care (<i>flexibility in adapting care to individual's needs and circumstances</i>) ✓ Consistency in care: adherence to cancer care. Applied from primary care, a measure of compliance in preventive care for cancer survivors ✓ Satisfaction with coordination of care (EORTC-SAT32) ✓ Delays/waiting time ✓ Symptoms relapse; worsening conditions ✓ Hospitalizations; emergency visits |
| | <p>Relational continuity <i>Ongoing therapeutic relationship between a patient and one provider. Bridges past to current care. Provides a link to future care.</i> (Haggerty et al., 2003)</p> | <ul style="list-style-type: none"> • Maintaining an ongoing relationship • Being easily accessible through the cancer continuum • Mapping on the cancer trajectory how the professional navigator is involved and until when • Being part of an oncology team • Being trusted by health providers and team members | <ul style="list-style-type: none"> • Effective professional navigator / patient communication (<i>bridges not only past to current care ; a link to future care</i>) ✓ Extent to which the same provider sees the patient in different settings ✓ Strength of patient-provider affiliation (e.g., PCAT; satisfaction with providers) |

| Dimension | Concepts | Process/Functions | Outcomes |
|--|--|--|---|
| <p style="text-align: center;">PROMOTING Patient and family empowerment (care providers as supportive partners in care) (Clinical functions of the role) (Dimension patient-centered)</p> | <p>Active coping <i>Process of taking active steps to try to remove or circumvent the stressor or to ameliorate its effects. (Carver et al., 1989)</i></p> | <ul style="list-style-type: none"> Assisting the patient to actively obtain information, support, and referral they needed Enhancing or reinforcing the patient’s senses of autonomy (self-care), and self-determination through education and support to maintain their sense of control and quality of life Reinforcing active coping Facilitating problem solving Facilitating decision making Setting and prioritizing goals | <ul style="list-style-type: none"> Perceived sense of mastery for self-care and self-action to manage family/social, practical problems (e.g., CASE-cancer) Capacity to cope with family/ social, practical changes (e.g., active coping strategies - planning, problem solving, etc.—(e.g., COPE; CHIP; CSE) Numbers of cancer related problems (e.g., IRLE-C) |
| | <p>Cancer self-management <i>Supporting the person/family and reinforcing his/her ability to accept the illness and regain control, regardless of prognosis. (Bulsara et al., 2006)</i></p> | <ul style="list-style-type: none"> Assessing and monitoring symptoms Providing or facilitating symptom management Assisting and reinforcing the patient in adjusting to and managing their altered health state and symptoms proactively, not reactively, through timely and tailored information and self-care instructions Reinforcing self-care behaviors Assisting in following individualized care plan Supporting the patient in decision making Supporting the patient/family on how to negotiate care (patient advocacy) Optimizing self-care capabilities/skills Educating, modeling and coaching to facilitate behavioral changes/patient/family | <ul style="list-style-type: none"> Unmet physical needs (e.g., SCNS) Symptoms distress scale Decisions to be made involve choices about treatment options and lifestyles changes (e.g., decision making scale; PES) Perceived sense of mastery for self-care and self-action to manage cancer, treatment, physical side effects (e.g., CASE-Cancer; heiQ; SE-Lorig) |
| | <p>Supportive care <i>Providing the necessary services as defined by those living with or affected by cancer to meet their physical, informational, practical, emotional, psychological, social, and spiritual needs. (Fitch, 2008)</i></p> | <ul style="list-style-type: none"> Providing access to supportive care through screening, assessment, direct care/intervention, and referral Screening for distress and conducting comprehensive supportive care needs assessment Identifying unmet supportive care needs Educating on distress and distress management Assessing available support and reinforcing it Supporting patient/family to mobilize their own resources and to explore new ones Providing transitional support Identifying policies or structural barriers limiting access to supportive care Facilitating the development of community and health care resources (leadership) Referring (mobilizing resources and services within the cancer care organization and the community to address unmet supportive care needs) | <ul style="list-style-type: none"> Unmet psychological, social, spiritual and practical needs (e.g., SCNS; CARE; IRLE-C) Emotional distress (e.g., POMS; HADS; PSSCAN) Emotional/spiritual (e.g., QoL - FACIT) Perceived support (e.g., MOS; PSSCAN) |

Fillion et al., 2012

Appendix I: Core Competencies Framework

(Cook et al., 2012)

| Dimension 1: Facilitating continuity of care | | | |
|--|---|---|--|
| <i>The patient appraises the experience of care as coherent and connected</i> | | | |
| Concepts | Key Functions | Domains of Practice* | Core Competencies |
| <p>Informational continuity <i>Use of information, disease or person focused, to make current care appropriate for each individual. Information is relevant to link care from one provider to another and from one healthcare event to another.</i> (Haggerty et al., 2003)</p> | <ul style="list-style-type: none"> - Having access to, and understand, high level of information on the cancer patients and their care - Providing timely and tailored information and advice to the interdisciplinary team(s) and cancer patients (<i>patient centered information</i>) - Working closely with the interdisciplinary team(s) to improve continuity of the information and knowledge of family/patients' needs and changes - Using communication tools and strategies to increase continuity of information | <p>Facilitating continuity of care and navigating the system <i>Promoting and facilitating continuity of care across cancer settings and between health care providers by sharing information on the individual/families' current situation goals, planned care and goals. Assisting the individual to navigate the health care system through understanding its situation, system and process and providing them with strategies to work within the system</i></p> | <p>To facilitate a collaborative approach by helping the patient/family and the health professionals to work as a team</p> <ul style="list-style-type: none"> ✓ To serve as the conduit of information between patient and health care team ✓ To provide linkage between the cancer system and community resources ✓ Utilize information beyond the medical conditions to include patient values, preferences, and social context ✓ Share information about the changing needs of patients as they move across the cancer continuum ✓ Provide information to patients and families across the cancer continuum, through transitions and changes in goals of care |
| <p>Management continuity <i>A consistent and coherent approach to the management of cancer that is responsive to a patient's changing needs. Providing a sense of predictability and security in future care for both patients and providers.</i> (Haggerty et al., 2003)</p> | <ul style="list-style-type: none"> - Conducting comprehensive screening and needs and resources assessment (<i>initial and ongoing</i>) - Matching unmet needs with services, resources available and support systems within the cancer care organization and the community - Identifying lack of resources, finding temporary solutions and reporting the system gaps - Mapping continuum of care; explaining treatment and care plans; minimizing uncertainty (<i>patient orientation</i>); decreasing barriers to cancer care adherence - Referring and communicating with hospital and community teams - Doing prompt liaison - Facilitating coordination and organization of medical/psychosocial care (<i>using care pathways</i>) - Contributing to the elaboration and application of the interdisciplinary care plan / nursing care plan - Contributing to interprofessional collaboration (<i>hospital and community settings</i>) | <p>Comprehensive health assessment <i>Conducting timely and comprehensive assessments of the health and supportive care needs of the individual with cancer and their families across the cancer continuum using a systematic approach that is sensitive to language and culture</i></p> | <p>To facilitate a coordinated approach by using assessment skills to identify and address changing health and supportive care needs throughout the cancer continuum</p> <ul style="list-style-type: none"> ✓ Conducts a comprehensive assessment, using a systematic approach of the health and supportive care needs that include individuals response to cancer individuals main concerns, goals and understanding of prognosis ✓ The assessment considers the situational context and needs and responses of the individual and family in determining the scope and depth of the assessment |

| | | | |
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| <p>Relational continuity <i>A therapeutic relationship between a patient and at least one provider, who develops accumulated knowledge of the patient as a person, and bridges past, to current and future care.</i> <i>(Haggerty et al., 2003)</i></p> | <ul style="list-style-type: none"> - Initiating and maintaining an ongoing relationship with the cancer patient - Being easily accessible through the cancer continuum - Mapping on the cancer trajectory how the professional navigator is involved and until when - Being part of an oncology team - Being trusted by health providers and team(s) members | <p>Supportive and therapeutic relationships Engaging in caring and therapeutic relationships with individual patients and their families Relationships are supportive and sensitive to changing physical and psychosocial-spiritual responses</p> | <p>To establish a therapeutic relationship with patients/families by being a consistent link between the patient, the health team, the hospital, and community services throughout the cancer continuum</p> <ul style="list-style-type: none"> ✓ To build a therapeutic relationship through the use of communication skills and engaging in conversations that explore fears and concerns related to living with cancer disease progression, mortality, dying and sexual health issues ✓ Making referrals to other health professionals as appropriate ✓ Serves as a key contact for patients and families at different phases of the patient journey |
|--|---|--|--|

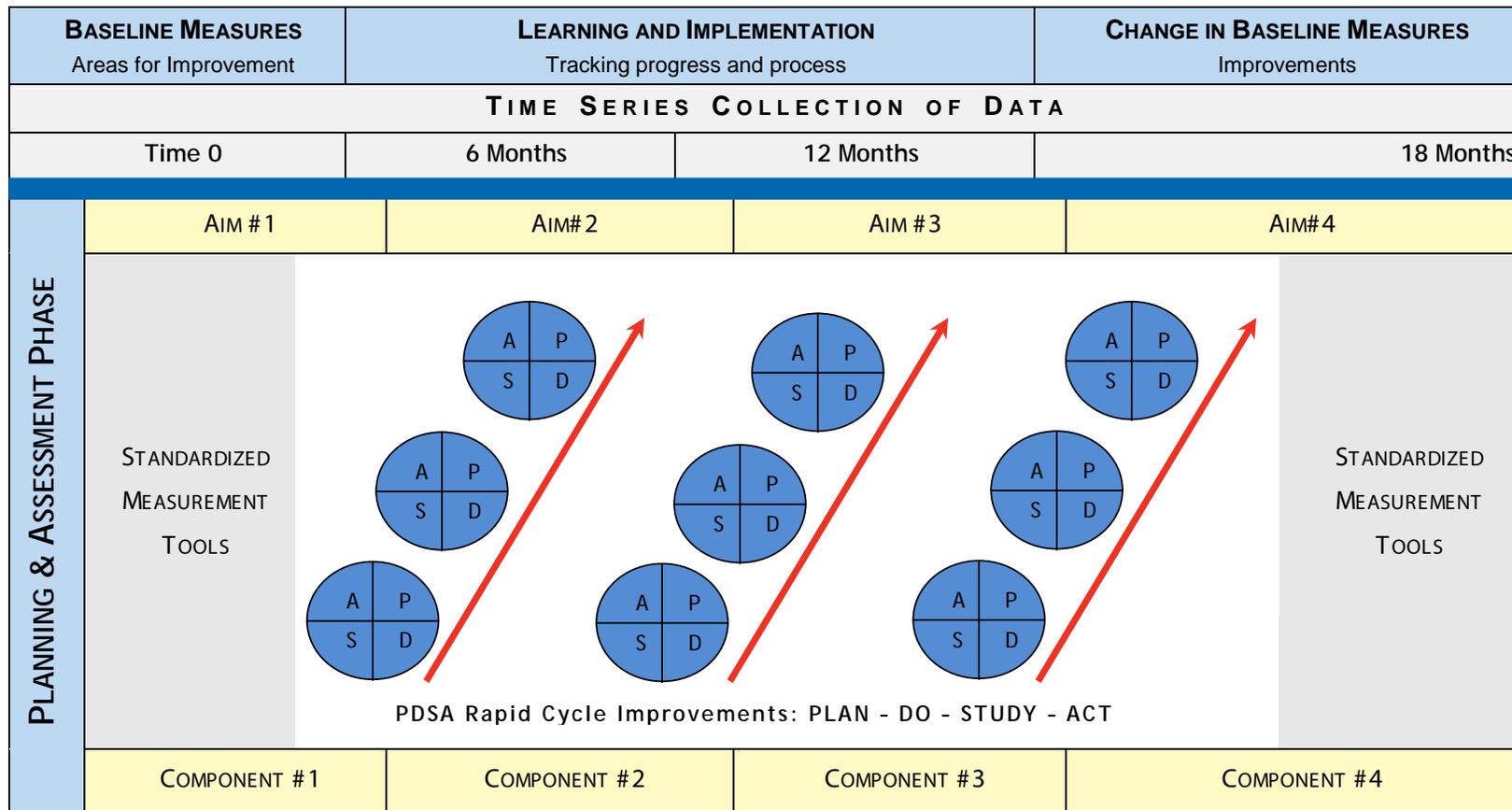
*Note: Domains of practice from Canadian Association of Nurses in Oncology (CANO)

| Dimension 2: Patient and family empowerment <i>The patient perceives the care providers as supportive partners in care</i> | | | |
|--|---|--|--|
| Concepts | Key Functions | Domains of Practice* | Core Competencies |
| <p>Active coping <i>Process of taking active steps to try to remove or circumvent the stressor or to ameliorate its effects.</i> (Carver et al., 1989)</p> | <ul style="list-style-type: none"> - Assisting the patient/family to actively obtain information, support, and referral they needed - Enhancing or reinforcing the patient/family's senses of autonomy (self-care), and self-determination through education and support to maintain their sense of control and quality of life - Enhancing recognition of patient/family's inner resources - Reinforcing active coping - Facilitating problem solving - Facilitating decision making - Setting and prioritizing goals | <p>Teaching and coaching Preparing individuals with cancer and their families for the many different aspects of the cancer experience Providing education, psychosocial-spiritual support and counseling across the continuum of care</p> <p>Decision-making and advocacy In collaboration with other interprofessional team members, facilitates self-determination and informed decision-making for individual and family. Advocate on behalf of the patient/family by communicating and documenting their preferred approach to care</p> | <p>To provide individualized information and education, based on their need, education level and situation using evidence based strategies to help patients and families cope</p> <ul style="list-style-type: none"> ✓ Assess individuals readiness to learn, learning styles, preferred depth of, and role in, decision-making ✓ Be aware of different aspects of the cancer experience and provide relevant "just in time" education as well as reinforcing education given by others ✓ Possess sufficient knowledge to discuss in depth aspects of treatment options and side effects, disease process, and management within various clinical and social contexts ✓ Possess negotiation and collaboration skills to enable appropriate advocacy on behalf of patient/family ✓ Help patient mobilize their own resources and explore new ones ✓ Mobilize resources and services within cancer organizations and communities to address needs |

| | | | |
|---|--|---|--|
| <p>Cancer self-management <i>Supporting the person/family and reinforcing his/her ability to accept the illness and regain control, regardless of prognosis. (Bulsara et al., 2006)</i></p> | <ul style="list-style-type: none"> - Assessing and monitoring symptoms - Providing or facilitating symptom management - Assisting and reinforcing the patient in adjusting to and managing their altered health state and symptoms pro-actively, not reactively, though timely and tailored information and self-care instructions - Reinforcing self-care behaviors - Assisting in following individualized treatment and care plans - Supporting the patient/family in decision making and cancer transition (<i>palliative care</i>) - Supporting the patient/family on how to negotiate care (<i>advocacy role</i>) - Optimizing self-care capabilities/skills - Educating, modeling and coaching to facilitate patient/family and team(s) members behavioral changes toward patient-centered care (<i>hospital and community resources</i>) | <p>Management of cancer symptoms and treatment side effects Integrating and applying in-depth knowledge of cancer pathophysiology, disease progression, treatment modalities, treatment side effects and complications and symptom problems to assess plan, implement and evaluate the outcomes of best practices/evidence-based care and other clinical intervention</p> | <p>To work with the patient and family to understand and manage the care plan and associated side-effects, symptoms and complications</p> <ul style="list-style-type: none"> ✓ To understand the cancer experience and to engage in conversations comfortably about different needs, feelings, fears, concerns, losses that the individual and family may encounter throughout the cancer journey ✓ Prepares the patient/family to self-manage and anticipate problems and issues associated with treatment side effects and symptoms of standard treatments ✓ Uses best practice/evidence based interventions to prevent or minimize problems/symptoms as they occur |
| <p>Supportive Care <i>Providing the necessary services as defined by those living with or affected by cancer to meet their physical, informational, practical, emotional, psychological, social, and spiritual needs. (Fitch, 2008)</i></p> | <ul style="list-style-type: none"> - Providing access to supportive care through screening, assessment, direct care/intervention, and referral - Screening for distress and conducting comprehensive supportive care needs and resources assessment - Identifying unmet supportive care needs - Educating on distress and distress management - Assessing available support and reinforcing it - Supporting patient/family to mobilize their own resources and to explore new ones - Providing transitional support - Identifying policies or structural barriers limiting access to supportive care and suggesting ways to address it - Assisting and facilitating the development of community and health care resources (<i>leadership</i>) - Referring (<i>mobilizing resources and services within the cancer care organization and the community to address unmet supportive care needs</i>) | <p>Supportive and therapeutic relationships Engagement in caring and therapeutic relationships with individuals who have cancer and their families. These relationships are supportive and sensitive to changes in physical, psychosocial-spiritual responses</p> | <p>To identify multiple physical, psychological, social, sexual and spiritual needs of clients throughout the cancer continuum and provide supportive care interventions and referrals in a collaborative multidisciplinary approach to care</p> <ul style="list-style-type: none"> ✓ To identify, validate and prioritize potential and actual physical, psychological, social, sexual and spiritual needs through routine screening and assessment of clients ✓ Collaborate with all members of the health care team to facilitate the provision of physical and emotional care\support to patients and families ✓ Utilize communication skills and apply knowledge of family dynamics and disease progression during interactions with patient and family |

Appendix J: Cancer Journey Quality Improvement and Evaluation Framework

Adapted from Health Quality Ontario by the Cancer Journey Portfolio Evaluation Team



| BASELINE MEASURES Areas for Improvement | LEARNING AND IMPLEMENTATION Tracking progress and process | | | CHANGE IN BASELINE MEASURES Improvements | |
|--|--|---|--|---|--|
| TIME SERIES COLLECTION OF DATA | | | | | |
| Time 0 | 6 Months | 12 Months | 18 Months | | |
| PHASE PLANNING & ASSESSMENT | AIM # 1 : <ul style="list-style-type: none"> 90% of target group is informed about Navigation function and availability | AIM# 2 : <ul style="list-style-type: none"> 90% of navigators hired will have knowledge and skills required for their scope of practice 90% of other healthcare providers will have knowledge and skills to facilitate integration of Navigation in team practice | AIM #3: <ul style="list-style-type: none"> 90% of navigators and other healthcare team members use best practice guidelines 90% of navigators and other healthcare staff report a high degree of satisfaction with integration of Navigation within teamwork | AIM# 4: <ul style="list-style-type: none"> 90% of navigated patients/families satisfied with process of care | |
| | Tools to measure: 1. Staff knowledge and skills 2. Staff satisfaction 3. Patient satisfaction/ Experience 4. Organizational Culture | <p>PDSA Rapid Cycle Improvements: PLAN - DO - STUDY - ACT</p> | | | Tools to measure: 1. Staff knowledge and skills 2. Staff satisfaction 3. Patient satisfaction/ Experience 4. Organizational Culture |
| | COMPONENT #1: Implementation of Navigation | COMPONENT #2: Staff Education and Training | COMPONENT #3: Teamwork and Collaboration | COMPONENT #4: Patient Engagement | |

Template for Implementing Navigation

Goal: To improve the cancer experience by providing Navigation services to patients and their families

Implementation of Navigation

Objective: To organize and plan implementation of a navigation program.

Activities: Develop detailed implementation plan, to include:

- Field preparation
- Stakeholder engagement
- Marketing
- Quality improvement and evaluation processes (data collection, measurement and feedback)

Process Outputs:

- Detailed implementation plan
- Data collection and reporting system
- # of patients informed about navigation function and availability
- # of patients receiving navigation

Process Outcome:

- Implementation of a Navigation program within a model of continuous Quality Improvement

End Outcome:

- Improved cancer care delivery with integrated Navigation services

Staff Education and Training

Objectives:

- To train navigators in the skills, knowledge and core competencies essential to their scope of practice.
- To educate other health care providers in the institution or community about the Navigation role and function and prepare them to support the integration of the navigator in the health care team.

Activities:

Conduct navigator training, including:

- Person-centered care
 - Best practices
 - Institutional guidelines
 - Evaluation and QI process
- Conduct training for other staff as above and also:
- Navigation definition and function
 - Navigator's role in the team
 - Changes in work culture (i.e., tracking processes, referrals, protocols)

Process Outputs:

- Training materials for navigators and other staff
- # of navigators hired and trained
- # training sessions for other staff
- # and category of staff attending sessions
- # navigators with skills and core competencies for practice
- # other staff equipped to support integration of Navigation in care process

Process Outcome:

- Increased capacity for Navigation as integrated part of cancer care process

Teamwork and Collaboration

Objective: To establish interprofessional collaboration among navigators and other team members.

Activities:

- Develop capacities of navigators and other health care team members to work in an interprofessional team, using best practices
- Develop and implement processes and protocols to promote team cooperation and communication

Process Outputs:

- Interprofessional model of care for Navigation
- Staff satisfaction with teamwork and integration of Navigation in care

Process Outcomes:

- Improved team collaboration
- Increased adherence to best practice guidelines

End outcomes:

- Improved coordination and continuity of care
- Increased cross-disciplinary knowledge of and support for Navigation

Patient Engagement

Objective: To improve the experience of the patient and family.

Activities: Implement processes to ensure that navigated patients and families are:

- Informed about the navigator's function
- Aware of the scope of the navigator's role (i.e., what to expect)
- Participating meaningfully in the navigation process (i.e., expressing needs, planning their care, making decisions)
- Participating meaningfully in evaluating the Navigation Program

Process Output:

- Patient/family satisfaction

Process Outcomes:

- Increased satisfaction with health-care
- Improved patient experience of care
- Increased knowledge of disease and the cancer care trajectory
- Increased awareness of available services and resources

Appendix L: Volunteer Navigation Position Description

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BC Cancer Agency

CARE & RESEARCH

An Agency of the Provincial Health Services Authority

VANCOUVER ISLAND

VOLUNTEER POSITION DESCRIPTION

Position: Lay Navigator

Effective: June 2011

Purpose: Provide non-medical information and support to patients and their families at key points in their cancer journey.

Time Commitment: 4 hours per month

Position Responsible to: Lay Navigation Coordinator & Volunteer Coordinator

Responsibilities:

- Sign in and out, document hours and read all messages using volunteer Impact
- Abide by the policies of the volunteer program
- Follow the lay navigation intervention protocol

Skills and Attributes:

Self as Navigator

- Self awareness: demonstrates appropriate use of self, limit setting, confidentiality
- Responsibility: demonstrates commitment to program, patients, ability to follow through, willingness to accept direction
- Personal growth: demonstrates commitment to learning and skill development
- Character: demonstrates integrity, honesty, respect and non-judgmental attitude
- Empowerment: fosters independence and self-advocacy in the helping relationship

Communication

- Demonstrates calm and caring presence
- Demonstrates empathic listening
- Invites dialogue through use of silence, encouragers, non-verbal communication

Knowledge/Information

- Demonstrates an ability to identify needs
- Demonstrates an ability to filter and select relevant information
- Demonstrates an ability to share information with pace, timing and quantity suited to listener.

Training & Support:

- General orientation to BCCA and VIC Volunteer Services
- Lay Navigation Training
- On-going educational opportunities
- De-briefing sessions

Benefits:

Gain valuable experience in a health care setting. Opportunity for one-on-one patient and family interactions. Opportunity to learn new skills or hone existing ones, and know that you are helping patients and their families,

Success Measures: Feedback from staff, volunteers and patients.

I have read and understand this position description:

Signature

Date