Your Resource Guide to

PATIENT NAVIGATION
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Whether you are considering starting up a patient navigation program at your institution or you are in the midst of implementing your program, there are materials in this guide that you can use to adopt or refine best practices in your program.

The literature in navigation is still evolving. It is especially limited in the areas of use during the treatment phase, formative evaluation and determining the cost-effectiveness of programs. While the writings assembled here are not exhaustive, they serve as a good starting place to develop a better understanding of patient navigation, how it can be implemented, and the outcomes already achieved. In addition to the literature, this guide includes toolkits, websites and other materials that share the successes of programs and lessons learned from experts in navigation.

To help you in your search of materials, the guide has been organized into four sections:

Section I. Introduction
This section provides a brief background about patient navigation, touching upon its history, trends in implementation, and its future direction.

Section II. Literature
This section includes a list of articles on patient navigation and other literature that provide a background on the issues that patient navigation is designed to address. For your convenience, this section has been broken into four types of materials.

Must Read Articles
These articles include those that have been recently published, have reported experimental trials, or have been cited several times in the literature. Annotated bibliographies have been provided and the articles have been organized by type.

Further Reading
These are articles, opinions, and editorials that further describe the research on patient navigation. Some of these articles provide a more detailed background for the must-read articles, while others help to give a different perspective on the uses and interpretation of patient navigation. A brief comment is provided to assist in identifying the major thrust of the material; these articles are organized by type.
Technical Reports
These include major reports on navigation that give more substantial and specialized information. Brief comments are provided on the content of the reports.

Background Articles
This list of articles include those papers which help to provide some background on the issues that patient navigation has been developed to address. These articles are listed without comment.

Section III. Getting Started
This section will help you in planning and beginning your patient navigation program. It includes materials on how to assess the need for a program, how to determine the value of your program to your institution, and how to include evaluation into your efforts from the inception. It is based on present best practices in the field.

Section IV. Toolkits and Other Resources
This section provides a listing and description of toolkits, websites and other resources that you can use to help develop or improve your own patient navigation program. The toolkits include materials to support your program and help prepare personnel for the tasks to be accomplished. The websites provide materials and resources, along with the opportunity to find up-to-date information through postings from experts, news alerts or forums.

We hope that this resource guide will help connect you with the tools and information you need to help make your program more effective for your institution and for your community.
In 1989, the American Cancer Society (ACS), chaired by its National President Harold Freeman, M.D., conducted a series of hearings throughout America to hear the testimony of poor Americans who had been diagnosed with cancer (Freeman, 2004). Based on these hearings, the American Cancer Society issued its Report to the Nation on Cancer in the Poor, which highlighted the following critical issues:

- Poor people meet significant barriers when they attempt to seek diagnosis and treatment of cancer.
- Poor people and their families make sacrifices in order to obtain cancer care and often do not seek care because of barriers faced.
- Poor people experience more pain, suffering and death because of late disease.
- Fatalism about cancer is prevalent among the poor and prevents them from seeking care.

As a result of these findings, the first Patient Navigation Program was conceived and initiated in 1990 by Dr. Freeman at Harlem Hospital Center in New York City, funded by a grant from the American Cancer Society (Freeman, 2004).

Dr. Freeman, who coined the term “patient navigation”, introduced the concept as a new way to address some of the factors thought to be responsible for poor rates of screening, adherence to follow-up, and treatment for cancer among medically underserved communities. During the Harlem Cancer Education and Demonstration Project, Freeman and his colleagues trained lay individuals as patient navigators who would identify patients’ barriers to seeking care and would work with patients, care providers, and community resources to overcome these barriers (Freeman et al., 1995). Results from this study indicated that patient navigators had the potential to facilitate a patient’s timely movement along the cancer care continuum because they successfully addressed the barriers that would have otherwise prevented these patients from seeking care.

**Defining Patient Navigation**

Since this first study, patient navigation programs have been initiated across the United States and Canada. Many of these programs have been shaped by the needs of their community and institutions. As such, no universal definition for patient navigation exists (Dohan & Schrag, 2005). Table 1 provides the definitions and roles of patient navigation identified by some leaders in the field. While the definitions and tasks may differ, common themes across programs include:

- Providing intensive, personal assistance for patients
- Identifying and addressing patients’ barriers to seeking or receiving care
- Moving patients along cancer care continuum in a more timely manner
- Connecting patients to community and medical resources

As you will find in the literature, these themes appear again and again, regardless of the type of organization, type of navigator or navigation tasks.

**Types of Navigators**

In Freeman’s original model, patient navigators were lay individuals who were (continued on page 8)
### Table 1. Definitions of Patient Navigation

<table>
<thead>
<tr>
<th>Program</th>
<th>Definition and Role of Patient Navigation</th>
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<tr>
<td><strong>American Cancer Society Patient Navigator Program</strong></td>
<td>The goal of an ACS Patient Navigator Program is to deliver timely information and available programs, promote informed decision making and enhance the quality of life for patients undergoing cancer treatment by the optimal utilization of ACS services and programs. The role of the patient navigators, who are full-time employees, is to ensure that the individual needs of oncology patients, related to information and barriers to care, are queried and addressed using ACS and other resources, to provide assistance and improve the patients and caregivers treatment experience. The intention is to create an environment in which the ACS patient navigator is identified as an integral part of the delivery of service at the host site and in the community. Patient Navigator Programs are created in conjunction with an enthusiastic champion and partner at the facility, and require a collaborative agreement be reached between the host site facility and ACS Divisions. It is expected that all programs will adhere to national standards and guidelines set forth by the Society. (Personal communication, July 7, 2008, ACS)</td>
</tr>
<tr>
<td><strong>C-Change</strong></td>
<td>Individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality medical and psychosocial care from pre-diagnosis through all phases of the cancer experience. Navigation services and programs should be provided by culturally competent professional or non-professional persons in a variety of medical, organizational, advocacy or community settings. The type of navigation services will depend upon the type, severity, and/or complexity of identified barriers. (C-Change, PN Promotion Initiative Workgroup, 2005)</td>
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<tr>
<td><strong>National Cancer Institute</strong></td>
<td>&quot;Patient navigation&quot; in cancer care refers to the assistance offered to healthcare consumers (patients, survivors, families and caregivers) to help them access and then chart a course through the healthcare system and overcome any barriers to quality care. A patient navigator can be a registered nurse or a social worker who functions as a &quot;guide.&quot; Navigators help their patients move through the complexities of the healthcare system—getting them more timely treatment, more information about treatment options and preventive behaviors. For example, in one community, a navigator's job may be to coordinate transportation to medical care for patients since some residents may have to travel more than 100 miles to receive cancer treatment. The program is designed for the navigator to serve as a reliable ally to lean on for advice, support and direction. A navigator is someone who understands the patient's fears and hopes, and who removes barriers to effective care by coordinating services and increasing a cancer patient's chances for survival and quality of life. (NCI, 2005)</td>
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<tr>
<td><strong>Pfizer Oncology</strong></td>
<td>Patient navigation is a process by which an individual—a patient navigator—guides patients with a suspicious finding (i.e., test shows they may have cancer) through and around barriers in the complex cancer care system to help ensure timely diagnosis and treatment. (Pfizer Oncology, 2006)</td>
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knowledgeable about their community’s resources and also had an understanding of the medical setting. Today, institutions have adapted their navigation programs to include a variety of lay and professional navigators.

Lay navigators are used because of their connection to the community and their ability to help patients address non-medical barriers, such as lack of transportation or inability to pay for screening or treatment. Lay navigators have included paid personnel, but have also included volunteer cancer survivors who have provided patients with an even more personal level of emotional support and understanding (Steinberg et al., 2006).

An increasing number of institutions have adopted professional navigators. Social workers, nurses, and health educators have all been used in patient navigation (Christie et al., 2008; Darnell, 2007; Englestad et al., 2001) because of their strong understanding of the medical system and their experience communicating with other health care professionals like physicians, radiologists and surgeons (Battaglia et al., 2006).

In institutions with sufficient funding for navigation, a mixed model using lay and professional navigators has been used (Lantz et al., 2004). In the mixed model, the professional navigator may be used to guide the patient through the health care system and facilitate timely diagnostic follow-up or start of treatment, while the lay navigator works with the patient to ensure that non-medical issues do not interfere with the patient’s ability to attend appointments and procedures. Some institutions are using the terms clinical patient navigator and non-clinical patient navigator — describing the tasks the navigator is performing rather than who is filling the position.

Fitting Navigation into the Cancer Care Continuum

Regardless of what type of navigator has been used, patient navigation has traditionally been implemented in one of three stages along the cancer care continuum—screening, diagnostic follow-up, and treatment (Freeman, 2006). While the goal of navigation has been to reduce the length of time it takes for a patient to move along the cancer care continuum, many programs have implemented navigation to address only one of the three stages.

In the screening portion of the continuum, patient navigation has involved services such as explaining the purpose and process involved in cancer screening, reminding patients about screening appointments, rescheduling missed appointments, providing emotional support
and assisting patients in finding community resources, such as transportation and financial assistance for screening (Christie et al., 2008; Jandorf et al., 2005; Weber & Reilly, 1997). In a study on colorectal cancer screening, individuals who had received navigation services were more likely to have made and kept endoscopy appointments than non-navigated patients. In a study that used an intensive case management service to improve mammography use, more women who received the navigation services completed their mammograms than women who did not receive the intervention (Weber & Reilly, 1997).

When patient navigation has been used to facilitate timely diagnostic resolution after abnormal screening findings, navigator tasks have included those previously mentioned, as well as advocating for patients among the cancer care team to obtain timely appointments for further investigation of results and navigating patients through the health care setting (Battaglia et al., 2006; Ell et al., 2007; Ferrante et al., 2008). Among women who have received abnormal breast cancer findings, navigation services have been found to decrease the diagnostic interval (Ferrante et al., 2008) and improve the likelihood of adhering to follow up recommendations (Ell et al., 2007).

Although studies specifically on treatment have not been widely reported, continued navigation through the health care setting, streamlining of and reminders about appointments, and addressing non-medical barriers (e.g. insurance and finances, child care, transportation) can facilitate patients seeking treatment and can improve five-year survival rates (Freeman, 2006).

**Current Initiatives in Patient Navigation**

In the summer of 2005, President Bush signed into law the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005, which set aside $25 million to support grantees in recruiting, training and employing patient navigators. Under this act, patient navigators are intended to help individuals by:

- Acting as contacts for individuals seeking prevention or early detection services for cancer or other chronic diseases
- Facilitating the involvement of community organizations to provide better access to high-quality health care services to individuals at risk for, or who have, cancer or other chronic diseases
- Coordinating with the relevant health insurance ombudsman programs to provide information to such individuals about health coverage
- Notifying individuals of clinical trials
- Helping patients overcome barriers within the health care system to ensure prompt diagnostic and treatment resolution of an abnormal finding of cancer or other chronic disease
- Conducting ongoing outreach to health disparity populations (U.S. House, 109th Congress, 2005)

Support of patient navigation at the policy level has generated a nationwide interest in navigation and the breadth of its impact in a variety of settings. Some of the largest ongoing patient navigator programs in the U.S. include the American Cancer Society Navigator Program, the Medicare Cancer Prevention and Treatment Demonstration for Racial and Ethnic Minorities and the National Cancer Institute/Center to Reduce Cancer Health Disparities Patient Navigator Research Program. Because of their size and the variety of questions they aim to answer, these studies will help to
provide even more rigorous evidence needed to further build the momentum for patient navigation. Some of these programs have the funds and ability to support the involvement of new institutions looking to implement a navigator program.

The American Cancer Society Patient Navigator Program

Dr. Harold Freeman, with the support of the American Cancer Society, introduced the first patient navigation program for cancer at Harlem Hospital in 1990. The American Cancer Society launched its formal Patient Navigator Program in 2005. Today it has nearly 100 programs in a variety of healthcare settings including both public and private hospitals.

The ACS Patient Navigator Program involves the placement of trained ACS staff in strategically selected healthcare facilities that treat a large number of newly diagnosed and underserved cancer patients. The goal of an ACS Patient Navigator Program is to deliver timely information and available programs, promote informed decision making and enhance the quality of life for patients undergoing cancer treatment by the optimal utilization of ACS services and programs.

The role of the patient navigators, who are full-time employees, is to ensure that the individual needs of oncology patients, related to information and barriers to care, are queried and addressed using ACS and other resources, to provide assistance and improve the patients and caregivers treatment experience. The intention is to create an environment in which the ACS patient navigator is identified as an integral part of the delivery of service at the host site and in the community. Patient Navigator Programs are created in conjunction with an enthusiastic champion and partner at the facility, and require a collaborative agreement be reached between the host site facility and ACS Divisions. It is expected that all programs will adhere to national standards and guidelines set forth by the Society.

In 2007, AstraZeneca provided a $10 million gift to help expand the Patient Navigation program. The program will allow ACS to open 50 new patient navigator sites over the next five years. Numerous other generous private donors have contributed to the growth of the program in the last two years.

In 2008, the ACS and the NCI collaboratively hosted the third Annual National Patient Navigation Training Program. They present the evaluation analysis of their program in Calhoun et al. (2008). For further information, contact Angelina Esparza, MPH, RN, Director, ACS Patient Navigator Program (angelina.esparza@cancer.org). (Personal Communication, July 7, 2008, ACS)

Medicare Cancer Prevention and Treatment Demonstration for Racial and Ethnic Minorities

In 2006, The Centers for Medicare and Medicaid Services awarded four-year cooperative agreements to six demonstration sites in Montana/Utah, Hawaii, Texas, Maryland, New Jersey, and Michigan. Each site is implementing a randomized controlled design to study the impact of patient navigator programs on improving care for minority populations. In this $24-million program, navigators will navigate minorities with and without cancer through the healthcare system and facilitate their cancer screening, diagnosis, and treatment. Target populations include American Indians, Asian Americans and Pacific Islanders, Hispanics (Mexican Americans, Cubans and Puerto Ricans) and African Americans. Cancer sites included in this study are breast,
cervical, colorectal and prostate (CMS, 2006).

**National Cancer Institute/Center to Reduce Cancer Health Disparities Patient Navigator Research Program**

In October 2005, the NCI, with support of the American Cancer Society, awarded $25 million in grants to nine academic research institutions to establish the Patient Navigator Research Program (PNRP). Sites include Boston, Denver, Washington D.C., Tampa, Portland, Chicago, Rochester, San Antonio and three cities in Ohio. Each of these sites is developing patient navigator interventions that assist individuals who may have breast, cervical, colorectal or prostate cancer in decreasing the time between abnormal findings, diagnosis and treatment. Issues related to cost-effectiveness, type of navigator used, and location of navigator are also being investigated (DRA, 2007; NCI, 2006).

**Future Research and Application to Chronic Disease**

Given the psychosocial support and health benefits that cancer patients receive from patient navigation, there is a growing body of research that is investigating the application of patient navigation to other disease areas. Adaptations to patient navigation will be needed to make it appropriate to the needs of those facing longer-term disease. So far, patient navigation or related coordination services have been applied to diabetes (Ingersoll et al., 2005), palliative care (Fischer et al., 2007), and HIV/AIDS (Bradford et al., 2007). Further research will be needed to better understand the impact of patient navigation in these areas.
In an effort to promote evidence-influenced practices, this section provides an overview of the literature that has been published on patient navigation as of June 2008. Some papers refer to patient navigation directly, while others provide information on other patient navigation activities, such as care coordination or case management.

For your convenience, articles have been separated into four categories. Articles in the first two categories—Must Read and Further Reading—have been further organized by type of article.

**Must Read Articles** The articles include those that have been recently published, have reported experimental trials, or have been cited several times in the literature. For these articles, annotated bibliographies have been provided.

**Further Reading** These are articles, opinions, and editorials that help to further describe the research on patient navigation. Some of these articles provide a more detailed background for the must read articles, while others help to give a different perspective on the uses and interpretation of patient navigation. A brief comment is provided to assist in identifying the major thrust of the material.

**Technical Reports** These include major reports on navigation that give more substantial and specialized information. Brief comments are provided on the basic content of the reports.

**Background Articles** These articles include those papers which help to provide some background on the issues that patient navigation has been developed to address. They discuss the effects of delays in screening and treatment, factors that have been associated with these delays, and barriers that patients face along the cancer care continuum. They are listed without comment.

Through this small, pilot randomized controlled trial, the authors found that patients receiving the patient navigation intervention were more likely to complete colonoscopy screenings than non-navigated patients. The authors clearly outline the duties of the professional patient navigator, which included, but were not limited to, assisting patients with scheduling and rescheduling missed colonoscopy appointments, explaining procedures to patients in Spanish and English, and organizing transportation services needed for patients to get to colonoscopy appointments. The authors also outline the navigation process and timeline of services provided to patients.


Aimed at investigating interventions that address mammogram follow-up, the authors conducted a randomized controlled trial comparing adherence to follow up for women enrolled in the SAFe program and women not enrolled or receiving usual care. The SAFe program is designed to reduce the effect of barriers to follow-up by providing psychosocial counseling (conducted by a social worker) and risk assessment, health education, patient follow up and tracking, appointment reminders and system navigation (all conducted by a patient navigator). Women enrolled in the program were more likely to adhere to timely diagnostic resolution than women receiving usual care. More information about the SAFe program can be found in Ell, Padgett, et al., 2002 and Ell, Vourlekis, et al., 2002.


In this randomized controlled trial, the authors compare patient navigation with usual care in their effects on time to seeking diagnostic resolution and reducing women’s anxiety. The authors outline qualifications for the patient navigator, the training provided, as well as the services the navigator provided to participants. Overall, patient navigation was found to significantly reduce the diagnostic interval (control = 42.7 days, navigation = 25.0 days).

In this prospective clinical trial, the authors test whether a patient navigation program, combined with physician recommendation, facilitated medically underserved men and women seeking colorectal cancer screenings (fecal occult blood test, flexible sigmoidoscopy and/or colonoscopy). As in Christie et al. 2008’s later paper on a similar study, the authors provide a description of the navigation process provided to subjects. The navigator was a community member with an ethnic background similar to the study participants. Overall, those who received the navigator intervention were more likely to have completed colorectal cancer screening by endoscopy within six months than those subjects in the usual care group.


This randomized controlled trial compares the effects of an outreach worker intervention and a direct mailing of educational and video materials on North American Chinese women obtaining regular Pap smears. Although the authors do not refer to the outreach worker intervention as patient navigation, it does include many of the elements central to patient navigation. The outreach worker’s duties included provision of social support for women, providing cultural mediation between the women and health care facilities and provision of logistical assistance (including appointment-making, arranging interpreter services and assisting with transportation). Both the direct mail and outreach worker interventions were found to be statistically significant in improving screening behavior at one of the two study sites.


This study on the use of community health educators to improve mammography use does not bear a patient navigation label, but does exhibit many of the characteristics of patient navigation services. Activities of the community health educator included sending written reminders to have a mammogram done, case management services, patient education, appointment scheduling, as well as addressing non-medical needs such as finding transportation, obtaining financial assistance and providing personal counseling to empower patients to communicate with physicians. A significantly greater percentage of individuals who received the intervention were more likely to complete a mammogram than those in the control group. A cost-effective analysis of the intervention is also reported.

This non-randomized study aims to determine the effect of a patient navigator on women seeking timely follow up to abnormal breast cancer screening results. Subjects considered to have timely follow-up were those who attended a diagnostic evaluation visit within 120 days of the originally scheduled appointment. This time-frame was in part chosen because of evidence supporting that delays of 3-6 months in diagnosis and treatment can impact survival (Richards et al., 1999). The study outlines the navigator’s duties, which focused around case identification, identification of barriers to care, implementation of a care plan, tracking the patient through to completion, advocating for patients with cancer care providers, and making reminder and informational telephone calls to patients. The primary outcome of the study was that 78 percent of the intervention group had timely follow up compared to 64% of the pre-intervention group (OR = 2.0, p<0.0001). This suggests that patient navigators can help reduce women’s delays in seeking breast cancer care.


This is Harold Freeman’s landmark study that introduced the term patient navigation as an intervention designed to improve cancer screening and follow-up rates among the medically underserved. This paper describes the multi-phase study and highlights the process by which the patient navigation intervention evolved in its early phases. It is an example of how patient navigation must be tailored to the needs of the community and the institution where it is being implemented.


This Canadian retrospective cohort study investigated the effect of patient navigation on the timeliness of the diagnosis of breast abnormalities (measured by the interval between diagnostic imaging and a core biopsy procedure). The patient navigator used in this study was a health care worker and breast cancer survivor who served as a patient advocate by working with physicians to facilitate timely investigation of breast abnormalities and providing educational and emotional support to women. Other responsibilities of the navigator are explained and justified in the paper. The authors found that the navigator intervention resulted in a statistically significant decrease in waiting time.
time for a core biopsy (20 days before navigation was implemented and 14 days after navigation was implemented).

**Descriptive Studies**


A somewhat informal paper from Dr. Freeman in which he provides a brief description of patient navigation and summarizes the findings from the studies on the Harlem Hospital Center Breast Cancer Screening and Patient Navigator Program. References are made to Freeman and Wafshe 1989, Freeman et al. 1995, and Olulewo et al. 2003.


This NCI/CHCRD sponsored study investigates the use of patient navigation to lower cancer mortality rates for American Indians in the Northern Plains region. In this study, two patient navigator programs are utilized—(1) an embedded nurse navigator who assists patients who are undergoing treatment and (2) community health representatives who live and work on reservations to provide cancer education, network with local health resources and provide support to individuals returning home after cancer treatment. Detailed descriptions of both navigators’ duties are provided. In addition, preliminary data findings on the number of patients navigated and the impact of navigation on treatment completion rates are reported.


This article describes the development and implementation of a patient navigator program implemented in rural and urban sites in Western Pennsylvania. The authors provide information on the navigators’ qualifications, trainings, recruitment procedures and data management methods. The results reported include information on patient satisfaction, the number of patients navigated, and additional demographic information about the patients seen. In addition to reporting the main barriers identified, the authors also report the average time taken by patient navigators to resolve these barriers, both at the urban and rural sites.


The investigators describe the process of implementing a patient navigation program and how they addressed
challenges in implementation. It provides a helpful example of the program development process—from deciding whether to use a lay or professional navigator to defining navigators’ roles to describing the initial patient use of navigation services. This is one of the few articles that aims to lay out the formative evaluation component of establishing a patient navigation program and gives a good indication of common questions, challenges and decision-making moments that arise along the process.


This case study of the original site of patient navigation and two sites developed by the leadership of the original site uses site visits and interviews to provide a description of patient navigation, the navigation process and the responsibilities of navigators and program directors at these sites. In addition to their description of the navigation system, the authors also consider contextual issues related to navigation, such as funding, cultural competence and the overlap and uniqueness of navigation when compared with community health workers and case managers.

Reviews


This review aims to answer three questions (1) What is patient navigation? (2) How are programs organized? and (3) What is known about the effectiveness of the programs? Although the authors find no single standard definition of patient navigation in the literature, they identify two common definitions (barrier-focused and service-focused) and distinguish navigation from other cancer support services. Eleven navigator programs are highlighted and information about their sponsors, type of navigator (professional vs. lay) and the disease sites they address are provided. The authors also engage in a discussion about research designs and evaluation measures to consider for future navigator programs.


This most recent review identifies and summarizes published literature on patient navigation. The results cover topics such as definitions of navigation, navigator tasks, populations served by navigators and the efficacy of navigation at different phases along the cancer continuum. The authors conclude with a description of the National Cancer Institute’s Patient Navigation Research Program.

This description of a Native Sisters project (introduced in Burhansstipanov et al. 1998) compares the effects of telephone-delivered and face-to-face delivered interventions carried out by the patient navigators.


This study is not specifically about patient navigation, but more about a case management intervention in which a nurse case manager provides reminder services about gynecological appointments, follows up with missed appointments and incorporates a computerized database to help track the appropriate follow-up interval.


This study explores the perceptions of older women with breast cancer about nurse case managers.


This earlier report of Project SAFe (followed up in Ell et al. 2007) provides a more detailed description of the intervention reported in the later study.


Also an earlier report of Project SAFe (followed up in Ell et al. 2007), this focuses more on the findings as they relate to cervical cancer. The peer counselor reported here is referred to as a patient navigator in the later paper.
Descriptive Studies


This article more informally explores the Steinberg et al. 2006 study which implemented a lay navigator program.


The authors conduct a retrospective analysis of their study's sample population to study the demographic characteristics of those subjects who had undergone a colonoscopy. Please refer to Nash et al. 2006 for more information on the study.


This study investigates the use of consultation planning, a tool designed to help patients develop questions for their physicians before the doctor’s visit. It may serve as a tool for navigators to use in their work.


Bilingual educators implemented an intervention which included a group educational session, training on how to navigate the health care system, activities on goal setting, and navigation services (e.g. arranging appointments, language translation).


This retrospective analysis study investigates the impact of a combination of interventions designed to help patients overcome system barriers. Among this combination of interventions is a patient navigation intervention in which navigators assist patients with paperwork, schedule and remind patients about appointments and facilitate referrals to care providers.

A brief description of the Native Women's Wellness through Awareness (NAWWA) project’s Native Sisters program. These Native Sisters are lay Native American women who have been trained to assist other Native American women in seeking cancer screening and follow up. More on a related study can be read in Dignan et al. 2002.


This short article brings attention to the patient navigation research that is being conducted in Canada. More about the study reported in the article can be found in the Technical Papers section of this Resource Guide (Sociobehavioral Research Centre, BC Cancer Agency, 2005).


This Canadian study investigated the role and function of an oncology patient-navigator nurse in the head and neck oncology program of a university hospital center. Individuals with cancer and their families, the university’s caregivers and network partners were all interviewed to evaluate their perceptions of what the navigators services would be, how the navigator would be implemented, the usage of the navigator services and the reactions after the services were implemented.

A short article that provides an overview of the research and status of patient navigation as of 2006.


This article provides baseline characteristic data of the sample population of a study comparing three interventions to improve screening knowledge, attitudes and behavior. A description of the patient navigation intervention is provided. A follow-up report is expected.


One institution’s report on its assessment of patients’ needs and the changes made in their care services to address these needs, including the implementation of a nurse coordinator to help support patients in the decision-making process.


This article provides a description of case management and the impact, benefits and challenges of implementing case management.


A case study on using health navigators as interorganizational integrators who can help the uninsured obtain timely appointments and care.


This study investigated the application of the community health advisor model in three cancer programs that focused on either
breast or cervical cancer. One program, CHAAP, trained community volunteers to serve as community health advisor navigators who would help patients navigate the health care system.


This article compares the study population’s characteristics of cancer stage at diagnosis and demographics with those of Freeman & Wasfie’s 1989 study population. This paper reports findings on individuals who would have had access to free cancer screening clinics, educational programs and patient navigation services.


This article discusses the role of the nurse navigator in the cancer care continuum.


This commentary helps to explain the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 and explores the roles social workers can play in implementing patient navigation.


The authors explore the benefits and challenges of incorporating patient navigation into the palliative care setting.
Through this narrative report on patient navigation, the authors provide a detailed account of patient navigation, the context in which it was developed and the future direction of research. By taking on a more broad definition of patient navigation (a system, rather than a specific person), they include a variety of health professional titles in their report, particularly social workers. Resources, which include published articles and materials from different organizations’ websites, are referenced throughout the paper.

The authors of this paper aimed to identify existing patient navigation programs through a literature search of articles published between 1980 and 2001 and interviews with key informants about patient navigation across Canada. In addition to describing their findings on topics such as barriers to care and outcomes measured in the evaluation process, they also categorize studies according to three different types of navigation models. In the appendices, a list of resources is provided, articles of interest are highlighted, and annotated bibliographies of the papers reviewed are provided.


This paper reports the process and impact evaluation of the first 18 months of the Cancer Patient Program that was launched at three Canadian sites in 2002. Objectives of this evaluation included clarifying the role of the navigator, determining the effectiveness of processes used in navigation and measuring the impact of navigation on patients, health care professionals and the institutions where navigation was implemented. The evaluation was based on quantitative and qualitative data collection that incorporated input from stakeholders, such as patient navigators, community partners, staff and patients and their families.

This short paper provides descriptions of several navigator programs and toolkits for patient navigators. Programs described here include national programs under ACS, NCI/CRCHD, and CMS, as well as local programs. Tables are provided throughout to highlight each program’s location, partnering institutions, type of cancer addressed, and type of navigator used. A comparison table of the reported programs is provided at the end.


Although patient navigation is not the focus of this IOM report, it does bring to light many of the psychosocial issues (e.g. transportation and financial difficulties, emotional issues, lack of health information) faced by cancer patients that patient navigation has been designed to address. Topics covered include the effects of unmet psychosocial needs, appropriate health services and models for delivering care and policy support for delivering psychosocial services. A report brief for health care providers, as well as ordering information can be found at: [http://www.iom.edu/CMS/3809/34252/47228.aspx](http://www.iom.edu/CMS/3809/34252/47228.aspx)


This small pilot study had two aims: (1) To gain a better understanding about the need for patient navigation and the existing navigation models through a literature review and interviews and (2) To develop a test and pilot instruments and tools to structure navigator interventions. In spite of the small sample size, the authors concluded that navigation cannot be confined to a single model, but can be conducted in a systematic manner that allows the needs of the patients to be met. The authors provide recommendations on methods that could aid in this systematic approach. Some of the tools that were developed were found to be appropriate for use in future studies.


Many patients experience barriers to receiving adequate health care. In addition to health-related issues, patients often experience non-health-related obstacles. Finances, social support, literacy skills and transportation issues often seem insurmountable to patients in crisis, as well as those in need of routine health care. Underserved and uninsured populations, as well as minorities, the aged and those with limited literacy skills may experience even greater difficulty navigating the health care system.

These barriers can ultimately affect not only the patient, but health care providers, health care institutions and the health care system itself. Patients may miss scheduled appointments, misunderstand preparatory instructions causing procedures to be rescheduled and fail to follow treatment regimens, increasing the likelihood of worsening symptoms and possible hospitalization. Failure to receive, process and act upon health-related concerns can be measured in patient census, patient acuity and the financial bottom line of health care providers, their institutions and the utilization review of insurance companies.

Things to Consider

Patient navigation helps to address identified gaps and barriers experienced by patients. It can help diminish or eliminate those gaps and barriers, thereby facilitating optimal patient care and outcomes throughout the care continuum. The outcomes of patient navigation can be measured by cost savings and patient satisfaction. Patient navigators have been identified as an important weapon against disparities. As noted by Schwaderer and Itano, “Navigators can address insurance, financial, and logistical issues (e.g., transportation, appointment scheduling, child or elder care). They can provide understandable health education that may lessen fears of [cancer] diagnosis and treatment.” (2007).

When considering a patient navigation program there are five essential areas to consider:

- What are the gaps and barriers for your patient population?
- What have successful patient navigation programs done?
- How will you fund a patient navigation program?
- How will you staff a patient navigation program?
- How will you evaluate the program’s effectiveness?

Investigating the Gaps and Barriers for Your Patient Population

Every institution is different. Even institutions with similar services and programs can vary by location, patient demographics and institutional finances. Keep in mind that gaps and barriers may exist for both the institution and its patient population.
population. When considering the gaps and barriers experienced by patients, you cannot make any assumptions about what your patients need or want. The best way to determine your patients’ needs and wants is to ask them directly. Patient questionnaires and satisfaction surveys can illuminate gaps and barriers perceived by patients. An important note to remember is that gaps and barriers for your patient population may extend beyond the boundaries of your institution (e.g., transportation, insurance, child care, etc.).

**Learning from Successful Patient Navigation Programs**

Although patient navigation is still in its infancy, there already are lessons to be learned from programs that have achieved some successes. The most compelling rationale for implementing a patient navigation program within your institution can be found in the achievements of programs around the country.

“The Patient Navigation Program was established in Harlem, New York, in 1990 to address the dramatic disparities in breast cancer mortality among minority women in the community. The success of the Harlem Patient Navigation Program has provided the impetus for the development of many similar patient navigation programs across the country and for federal support for patient navigation research to address the critical need for effective interventions to eliminate cancer health disparities, particularly among minorities and the underserved” (Freeman, 2006).

The Urban Latino African American Cancer (ULAAC) Disparities Project in South Los Angeles designed and implemented a patient navigator program for underserved cancer patients in an urban, nonacademic community hospital setting. “Preliminary assessments of this program suggest that it has had a positive effect on minority and low-income cancer patients’ experience with care and reduces barriers to care” (Steinberg et al., 2006). A rural, multi-site patient navigator program involving five cancer institutions in Western Pennsylvania identified and addressed the concerns and issues of rural patients that often differ from the concerns and issues of urban dwellers (Schwaderer & Itano, 2007).

**Finding Funds for a Patient Navigation Program**

Funding your patient navigation program will depend on how you tailor your program. Once you have established the services you intend to provide, funding sources may become apparent. Currently, patient navigation is not a recognized reimbursed service (Vargas et al., 2008). You may need to incorporate a

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**Other Lessons Learned from Leaders in Navigation**

- An organizational needs assessment is a necessary starting point to identify gaps in services
- Promoting the program among staff and the community will help to get early buy-in from physicians, surgeons, and radiologists and build patient interest
- Open dialogue between cancer care staff and navigators will help to ensure cooperation among all members of the team and to establish more clearly defined roles and boundaries

-Comments from The Patient Navigation Workshop held in Philadelphia in 2007, Reported in Pfizer Oncology’s Expert Commentary from Linda Fleisher, MPH (www.patientnavigation.com)
number of resources, such as grants and internal institutional support to maintain your program.

**Staffing a Patient Navigation Program**

There is no one definition to describe who a patient navigator should be or what that person’s duties will entail. Generally, there are two categories of patient navigators — clinical and non-clinical. The dynamics of each institution and its patient population will dictate what professionals and/or community workers are best suited for your consideration as a patient navigator. Some institutions have chosen to utilize existing staff while others have found that a dedicated new-hire ensures a concentration of duties.

Once you have identified the gaps and barriers faced by your patient population, you will be better equipped to answer the question of how to staff the position of patient navigator. Regardless of whom you eventually hire, appropriate training in patient navigation, regulatory requirements, institutional orientation, cultural competency and disease-specific training will need to take place before your navigator is prepared to assist your patients on their journey through the health care system.

**Evaluating Your Program’s Effectiveness**

The old adage, “you can’t know where you are going unless you know where you have been” is very true. Evaluation of your patient navigation program’s effectiveness begins long before you implement a program. You must first identify what issues your patient navigation program will address and then establish your current norms as a baseline. Pre-program questionnaires, surveys, and financial reports may provide concrete documentation of areas in need of improvement.

After you have established the need for patient navigation and as you begin planning your program, you must also put in place a plan for periodic, ongoing monitoring and evaluation. This ongoing monitoring and evaluation can then be measured against your original baseline data for evidence of change and improvement.

Improved timeliness to diagnosis, reduction of patient anxiety, and increased overall satisfaction are measurable benefits of patient navigation (Ferrante et al., 2008). Patients have been receptive to and pleased with patient navigation because it coordinates services and provides them with guidance and support (Seek & Hogle, 2007). In addition, tracking the navigation program’s financial impact on your institution can be an important measure of effectiveness. As one example, the Denver Health Community Voices measured service utilization, charges and reimbursements for underserved men and found that with a monthly program cost of $6,229 they realized a return on investment (ROI) of 2.28:1.00, a savings of $95,941 annually (Whitley et al., 2006).

Established qualitative and quantitative measures, along with new and creative measures, can be employed to evaluate your patient navigation program.

“The purpose of navigation is not to replace or overlap existing roles, but to complement them by filling in gaps in services and proactively facilitate the delivery of care to all patients.”

-Excerpt from Pfizer Oncology’s Spring 2008 Expert Commentary from Linda Fleisher, MPH (www.patientnavigation.com)
**Tools to Build and Develop Your Own Program**

This section provides a list and description of toolkits and other resources that you can use to develop or to supplement your own patient navigation program. The toolkits include materials that you can use to support your program and prepare navigators for their tasks. The websites offer the opportunity to find materials and up-to-date information through postings from experts, news alerts or forums where professionals involved in navigation share their experiences. Some resources that are site specific can be adapted to non-site-specific uses. All resources listed are accurate as of June 2008.

**Cancer Patient Navigation: Care for Your Community**

**Audience:** Organizations interested in promoting the concept and development of community-based patient navigation programs

**Sponsor:** C-Change, an organization comprised of the nation's key cancer leaders from government, business, and nonprofit sectors

**Description:** This toolkit gives information about what patient navigation is, and why it is important. It is intended to serve as a marketing tool for promoting the concept and development of community-based patient navigation programs, rather than detail how to create a program. The site provides links to different elements of the toolkit. A hard copy of the toolkit, which includes the DVD video, can be ordered at the website.

**Content:** The toolkit contains three elements:

A **video** that engages the viewer with the human, community, and organizational story of cancer patient navigation. The compelling stories of three communities of care (Oakland, California; Chicago, Illinois; and Jackson, Kentucky) working to meet the needs of cancer patients are told. The video also contains interviews with several experts on patient navigation.

A **web site** that provides an overview of patient navigation and houses links to resources and information. Cancer patient navigation documents, an overview of the benefits of cancer patient navigation to patients and organizations, recommended components and organizational considerations when starting a patient navigation program, and resources such as a reading list, links and useful tools are all found on this web site. In addition, you will find downloadable pdfs of many key documents as well as a model press release and advertisements.

A **press kit** that contains promotional materials, press releases, advertisements, and a brochure about cancer patient navigation.

**URL:** [http://www.cancerpatientnavigation.org](http://www.cancerpatientnavigation.org)
Breast Health Patient Navigator Resource Kit

**Audience:** Facilities that wish to start a navigation program for breast cancer patients

**Sponsor:** The Healthcare Association of New York State (HANYS)

**Description:** This toolkit includes comprehensive templates to help implement a breast health patient navigator program. It is designed to help facilities create a program that fits their individual needs.

**Contents:** The toolkit provides guides to establish the program, facilitate data collection and evaluation and generate media coverage, including:

- Step-by-step program implementation guide
- Powerpoint presentation to educate hospital management
- Program description template modifiable to facility’s needs
- Patient navigator position description with sample responsibilities
- Printed materials to advertise program
- Policies and procedures for specific functions and responsibilities
- Data collection tools, such as intake forms, patient satisfaction survey and tracking tools

**To Order:** [www.hanys.org/bcdp/resource_kits/pnresourcekit.cfm](http://www.hanys.org/bcdp/resource_kits/pnresourcekit.cfm)

Patient Navigation in Cancer Care: Guiding Patients to Quality Outcomes™

**Audience:** Program champions (individuals who initiate and support implementation of a patient navigation program within a given organization) and navigators

**Sponsor:** Pfizer, Inc., with guidance from team of experts in field of cancer care, in cooperation with The Healthcare Association of New York State (HANYS) and Dr. Harold P. Freeman, president and founder of The Ralph Lauren Center for Cancer Care and Prevention.

**Description:** The tool kit includes training manuals to provide resources and support for program champions and to prepare patient navigators for their responsibilities.

**Contents:** This resource includes four manuals:

- **Establishing a Patient Navigation Program: An Implementation Guide for the Program Champion.** Designed to assist the champion in promoting the concept of navigation within an organization, it provides resources to help implement the program
- **Navigation Pathways: The Patient Navigator Training Manual.** Clearly defines the role and responsibilities of patient navigators and provides resources to help them guide patients through the health care system
- **Breast Cancer Pathways: A Resource Guide for the Patient Navigator.** Contains appropriate information specific to breast cancer to
educate navigators on the special considerations of this disease.
Includes tools and resources necessary to assist patients with breast cancer

- Colorectal Cancer Pathways: A Resource Guide for the Patient Navigator. Designed to educate navigators about the special considerations of patients with colorectal cancer

URL: www.patientnavigation.com

C-Change: Collaborating to Conquer Cancer

**Audience:** Patient navigators and organizations that wish to start a program

**Sponsor:** C-Change, an organization comprised of the nation's key cancer leaders from government, business, and nonprofit sectors

**Description:** One of the underlying principles of C-Change is to leverage the leadership and expertise of all sectors of society to eliminate cancer as a major public health problem at the earliest possible time. C-Change is both a forum and a catalyst for identifying issues and major challenges facing the cancer community and for initiating collaborative actions to complement the efforts of individual C-Change Members. Among the resources on this site are the Cancer Patient Navigation: Care for your Community toolkit (see Toolkits) and other publications on patient navigation.

**Content:** Links to a variety of publications, resources and organizations that focus on cancer prevention, research, and advocacy.

URL: http://c-changetogether.org
Other Resources (cont’d)

Breast Health Navigator.com, EduCare, Inc.

**Audience:** Nurse navigators

**Sponsor:** EduCare Inc., North Charleston, South Carolina

**Description:** EduCare, Inc. provides periodic trainings for nurse navigators. This site gives information on these trainings, including certification in breast health education and strategic planning of a breast health center.

**Content:** Provides links to patient education products and a forum specifically for nurse navigators who have been trained and certified by EduCare, Inc.

**URL:** [www.breasthealthcare.com](http://www.breasthealthcare.com)

Harold P. Freeman Patient Navigation Institute

**Audience:** Individuals associated with organizations that may develop or expand patient navigation programs

**Sponsor:** The Harold P. Freeman Patient Navigation Institute

**Description:** The Harold P. Freeman Patient Navigation Institute, launched in 2007 with a $2.5 million grant from the Amgen Foundation, is the first certification and training program for patient navigators. Through a 3-day training course, attendees are trained in the H.P. Freeman model of patient navigation and equipped with tools to tailor navigation to the needs of their institutions.

**Content:** Information about the Institute’s certification and training program, application form, fact sheets on the Institute and a background on patient navigation

**URL:** [www.hpfreemanpni.org](http://www.hpfreemanpni.org)


**Audience:** Patient navigators

**Sponsor:** National Cancer Institute

**Description:** Downloadable PDF of the National Cancer Institute’s resource manual. This resource manual was designed to provide a tool for patient navigators to use when sharing information with patients facing cancer, specifically breast, cervical, prostate, and colorectal cancers. It provides a list of NCI documents, national organizations and a place for navigators to insert a list of community resources available to their patients.

**Content:** NCI Patient Navigation Research Program Resource Manual

**URL:** [http://ncipoetqa.cancer.gov/PatientNavigator/Index.cfm](http://ncipoetqa.cancer.gov/PatientNavigator/Index.cfm)
Center to Reduce Cancer Health Disparities, Patient Navigation Program

**Audience:** Patient navigators and organizations that wish to start a program

**Sponsor:** National Cancer Institute

**Description:** The site gives information about patient navigation and the NCI’s Patient Navigation Research Program, which is aimed at developing and testing patient navigation interventions across the nation. Information on the research sites is provided. Links to the Northwest Native American Patient Navigation Pilot Program are also on the site.

**Content:** Description of patient navigation and its uses

**URL:** [http://crchd.cancer.gov/pnp/background.html](http://crchd.cancer.gov/pnp/background.html)

Patient Navigation in Cancer Care: Guiding Patients to Quality Outcomes™

**Audience:** Health care professionals and organizations interested in learning about the benefits of patient navigation. This site is not intended for use by patients.

**Sponsor:** Pfizer, Inc.

**Description:** *Patient Navigation in Cancer Care* is intended to serve as a paradigm for creating patient navigation programs across the United States. The content and structure of this Web site supplement that provided in the multimedia tool kit, *Patient Navigation in Cancer Care: Guiding Patients to Quality Outcomes™*, which is available through your Pfizer representative (see Toolkits). The site and toolkit have been developed to help any organization implement a patient navigation program. Registration (free) is required to access all areas of the websites including “Expert Commentaries” from those researching and implementing patient navigation, “Best Practices” shared by organizations who have successfully implemented navigator programs and other support tools and information specifically for navigators.

**Content:** This site has been developed to provide a broad understanding of patient navigation in cancer care. The site also provides guiding principles and models for individuals who are or who would like to become patient navigators in their organization or community.

**URL:** [www.patientnavigation.com](http://www.patientnavigation.com)


Images

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