

# How the NCCCP is Using Patient Navigation to Help Reduce Cancer Disparities

by Jay R. Swanson, RN, BSN, OCN®; Thomas Asfeldt, RN, BAN, MBA; Carolyn Kalaskie, MS; Patricia Strusowski, MS, RN; Eileen Van Pelt, RN, OCN®; Rachel Oelmann, MBA; Dawn Parsons, RN, OCN®; Maria Gonzalez, BS; Mitchell Berger, MD, MMM, CPE, FACP

Patient navigation is a key focus of the NCCCP Disparities program pillar. This article is a brief account, from the NCCCP Disparities White Paper, of how the network sites developed and implemented patient navigation programs as part of efforts to reduce cancer healthcare disparities.

## Navigation at NCCCP Sites

While navigation services vary widely based on patient needs and available resources, NCCCP navigation programs are consistent, offering:

- Patient education on disease and treatment
- Connection with local resources for financial or emotional support
- Facilitation of screening for abnormal findings and scheduling follow-up or staging appointments
- Quick referral to resolution
- Collaboration with the multidisciplinary and clinical trial teams
- Provision of a single contact for the patient to connect with, in some cases in a culturally sensitive environment, and obtain support.

NCCCP sites employed a variety of approaches to patient navigation, including:

- **Outreach navigation:** often to direct people from disparate populations into screening and through the abnormal result resolution process. The purpose of outreach navigation is to facilitate early detection to reduce disease mortality. The navigator helps ensure the population has access to screenings by collaborating with community partners to provide health fairs, community screening events, mobile mammography, and cancer awareness education programs. Outreach navigators act as a liaison with local resources.
- **Abnormal-to-disease navigation:** where navigators work with diagnostic areas of the hospital system (e.g., endoscopy, mammography, radiology) to help move patients from an abnormal finding to resolution for a cancer diagnosis. They provide patients with information and resources to help with finances and reduce barriers to resolving abnormal findings.

Patients are assigned to another navigator for continuation of services.

- **Diagnosis-to-treatment navigation:** that has navigators assisting patients from an initial diagnosis through the completion of treatment.
- **Inpatient navigation:** to assist patients who are hospitalized due to the acute needs of a suspicious finding, new diagnosis, or the effects of treatment. The goal is to provide the patient with information to prevent future admission or inpatient stay and to get the patient on an effective treatment plan quickly.
- **Survivorship navigation:** to assist patients beyond treatment and through the course of late and long-term effects, follow-up appointments, and potential disease recurrence.

## Establishing a Patient Navigation Program

At the launch of the NCCCP, there was considerable variation in the provision of navigation services among the sites. One site had no patient navigation services. Working in conjunction with the NCCCP, this community cancer center decided to focus initial navigation services on breast cancer due to the community's disease morbidity and size. Reaching out to physicians to introduce and explain the navigator's role in breast cancer patient care was paramount to establishing the program. Demonstrating that navigation bridges gaps in care from the time of diagnosis through treatment and survivorship was essential to the success

of the early development of a navigation program. Furthermore, the navigator kept primary care physicians informed of their patients' care and provided smooth access through the healthcare system for patients and their families. The oncologists employed by this institution supported the addition of a nurse patient navigator.

Prior to NCCCP funding, another site expanded its program by adding a breast health specialist position, yet few program services had been established. This site formed a Breast Health Group composed of key people from medical oncology and the surgeon's office, along with other interdisciplinary team members. A positive result of this action was that patients began to meet with





At NCCCP site St. Joseph Hospital of Orange, Calif., a Pacific Islander patient navigator reviews a colorectal cancer educational flipchart culturally tailored for Native Hawaiian and Pacific Islanders.

the navigator at the time of diagnosis rather than after treatment. The navigator served as a central point of contact, a patient advocate, and a physician partner in patient education. The NCCCP site learned that less focus on the “ideal” navigation infrastructure and more focus on small changes that lead to improved process outcomes helped enhance its program.

### Strengthening Patient Navigation Programs

For sites with well-established patient navigation programs, NCCCP participation helped expand outreach with focused disparities efforts. Leveraging the NCCCP, these sites enhanced services to meet the needs of underserved populations across multiple counties in both rural and urban communities.

For example, prior to joining the network, one site had launched a physician-led, multidisciplinary Breast Cancer Action Team. The model used breast navigation that began with an abnormal finding (BIRADS 4 or 5 screening mammogram) and continued to resolution of finding, through treatment, and into survivorship. One key outcome measure was the time from a positive screening mammogram to resolution. Through NCCCP par-

ticipation and the program’s concentrated work, the site expanded community outreach efforts and cancer screenings; this resulted in an increased volume of patients with BIRADS category 4 or 5 screening mammograms. The addition of a diagnostic nurse navigator proved essential to their goals and activities.

As part of its disparate population focus, the NCCCP is concerned with the needs and issues within rural patient populations. One NCCCP site specifically identified rural areas and American Indians as target populations. With NCCCP funding, this site hired a regional navigator to focus on challenges unique to the specific communities. To determine how best to use the navigation services, two elements were crucial: trust from the disparate population and knowledge about community education and screening programs already in practice. The regional navigator traveled throughout rural communities and area reservations to meet with key staff members at healthcare programs. One goal of these meetings was to identify existing supportive programs so that cancer patients could enroll in them in their home communities. This collaboration built trust and allowed for further program development. The regional navigator identified a significant lack of edu-



NCCCP-site  
volunteer and  
prostate screening  
participant.

cation and understanding about cancer prevention and early detection. Free educational programs, such as the Cancer 101 series available through NCI's Spirit of Eagles program, were used to stress the importance of screening. This site's experience highlighted the importance of conducting fact-finding and trust building endeavors *before* developing a program. Understanding the needs of the community and working collaboratively to meet those needs are essential to building a successful program.

At another NCCCP site, the Community Health Outreach and Education (CHOE) department provided public awareness and access to cancer-screenings for state residents and high-risk populations. This NCCCP site conducted an inventory of existing programs related to established community and state efforts, including a review of their importance, relevance, and outcomes in terms of increasing cancer screenings in disparate populations. The site determined that continued efforts to provide resources for this outreach program were important. Choosing to focus on the African-American community, the site decided to start with HPV vaccinations. Once partnerships were formed, the site initiated a health fair event for OB/GYN adolescents. Part

of the goal was to offer cervical cancer screenings to parents and/or guardians of the targeted girls. The site also placed a cancer screening navigation nurse onsite during clinic hours to meet with patients and improve screening completion rates. Indirectly, the NCCCP site found that most state residents were unfamiliar with resource materials or local programs.

### Using Lay Navigators

While lay navigators are not clinically trained, they can provide some of the same services as their clinical counterparts. The focus of lay navigation tends to be on barriers to care and ways to address or mitigate those barriers for the patient. Often employed by either the hospital or the clinic, lay navigators may also be affiliated with an outside organization such as the American Cancer Society (ACS) or Community Networks Program (CNP). Use of culturally appropriate lay navigators for disparate populations is becoming more common in cancer care. Understanding cultural, geographic, or spiritual barriers to care is helpful for the lay navigator. The best approach is to pair a patient with a navigator of similar race or ethnic background. Pro-

## Recommendations for Expanding or Developing Successful Navigation Programs

For community cancer centers looking to establish or expand patient navigation services, NCCCP sites offer these recommendations.

- ✓ Assess program readiness prior to implementing a patient navigation program. Use tools, such as ACCC's Patient Navigation Pre-assessment Tool (<http://www.accc-cancer.org/education/pdf/PNTTOOLS2009/Pre-Assessment-Tool.pdf>) to evaluate program readiness and gather necessary information for project planning and development.
- ✓ Assess your program's current systems in relation to the needs of your community. Design the program so it fits with your organization's care delivery system. Clearly define the scope of the patient navigator's role. Establish how nurse navigation

- will interface with all disciplines and hospital support programs.
- ✓ Involve all key stakeholders. Engage cancer program administration and physicians *early on* in the process.
- ✓ Contact established successful navigation programs to learn from their experiences and challenges, and make use of existing forms and tools. Ask questions and adapt the information to meet the specific needs of your organization and patient population.
- ✓ Hire staff with experience in outreach and/or oncology. Consider hiring staff that is representative of the disparate community you are trying to serve.
- ✓ Ensure that all staff is aware of cultural issues specific to your community, including the special needs of local disparate populations.
- ✓ Educate all cancer program staff about your navigation program.
- ✓ Understand how patients access your healthcare delivery system and create mechanisms at those

- entry portals to refer patients to the navigator.
- ✓ Have the right programs and staffing in place to access care for your disparate patient populations. Community cancer centers need to help reduce barriers by using insurance counselors, financial counselors, and social service providers. Other barriers to consider include educational materials, language, cultural awareness, transportation, and trust.
- ✓ Use tracking and screening tools and patient satisfaction survey data to develop standards for your patient navigation program and services.
- ✓ Establish metrics to measure the program achievements and outcomes.
- ✓ Develop a disease-specific program (e.g., breast cancer navigation).
- ✓ Collaborate when possible. With proper collaboration, even data collection systems from different providers can work together to establish, focus, and meet project benchmarks.

gram services provided by the navigator include, but are not limited to:

- Helping with insurance issues
- Addressing barriers to care
- Offering lodging arrangements for patients at no cost
- Providing fuel cards to assist with transportation expenses
- Purchasing a wig for patients who desire one yet cannot afford it
- Providing general gift items (e.g., hats, scarves, lotion) to help cope with the symptoms of disease and side effects from treatment.

### Evaluating Navigation Services and Establishing Quality Tracking Metrics

Most services offered by patient navigators are non-billable. Therefore, patient navigation is a service that must demonstrate efficiency to justify its use of resources. While the support navigators offer patients is certainly valuable, community cancer centers often struggle to provide a business case to show that navigation services can also indirectly generate revenue. NCCCP sites found navigator programs help to:

- Reduce inpatient stays and ER visits
- Increase downstream revenue for other services
- Improve coordination of care
- Increase the number of referrals to the cancer center
- Reduce wait times from abnormal findings to diagnosis
- Improve patient satisfaction surveys
- Perform outreach in targeted areas of the community

- Direct disparate populations through the continuum of cancer care.

Navigator programs must be able to track appointments and patient concerns, along with other information. To help track information on breast cancer patients, the NCCCP developed the breast screening tracking tool (pages 50-51). Designed as a quality improvement tool, it can be used to track time from abnormal finding to diagnosis or resolution of abnormal finding, or to treatment. The tool is a complex spreadsheet divided into four main areas: Demographics, Screening and Diagnostics, Treatment, and Navigation. With the NCI goal of making clinical trials available to more patients in the community, the NCCCP incorporated a category on trial referral into the tool.

### Best Practice Sharing

Connecting patient navigation across all NCCCP pillars was important to the Disparities Subcommittee. Further, communication between program pillars provided new opportunities for sharing best practices, pooling resources, and decreasing redundancy.

The Disparities Subcommittee found collaboration—both within individual hospital networks and among NCCCP sites—was essential to developing, implementing, and/or expanding patient navigation services. This collaboration helped to validate the importance of navigation and to foster new ideas and opportunities. Best practice dis-

*continued on page 52*

# NCCCP BREAST SCREENING

DEMOGRAPHICS					
Patient Name		City	Zip	Day Phone	Ethnicity
ABNORMAL FINDINGS					
	Breast Exam Result and Date	Screening Mammogram Result and Date	Diagnostic Mammogram Result and Date	Ultrasound Result and Date	MRI Result and Date
DIAGNOSTIC INFORMATION					
	Date of Diagnosis/Resolution	Diagnosis	Definitive Diagnosis by: (what test)	Biopsy Results	Stage of Diagnosis
TREATMENT INFORMATION					
	High Risk Counseling Date	Genetic Test Results/Date	Clinical Trial Offered (Y/N)	Reasons not on Trial	Presented at Multi-Disciplinary Clinic/Conf prior to start of treatment?
	Chemotherapy				
	Date Started	Type of Chemo	Date Completed	Physician	Hormonal Therapy
NAVIGATOR					
	Name	Date Connected with Patient	Navigation Started	Referrals to Other Services (List)	Barriers to Care

# TRACKING TOOL – Version 2.0

	Race	Marital Status	Age Range	Insurance	Other	Activity that caused person to be screened (if any)
	Estrogen Status	Progesterone Status	HER2/NEU	Other		
	Time from definitive diagnosis to first appointment for treatment consult	Surgery Date	Type of Surgery	Surgeon/Physician		
Radiation Therapy						
	Date Started	Type of Radiation	Date Completed	Physician		
	Reasons for not completing testing/treatment					

# ...people are often unaware of navigators and the benefits their services can provide patients.

discussion included assessment tools, cultural considerations that may reduce barriers to care, appropriate programs for target populations, community partnerships, tracking and screening tools, and performance improvement activities.

## Conducting Patient Surveys

Navigator programs are demonstrating increased patient satisfaction with the patient navigator role.<sup>1</sup> NCCCP sites developed patient surveys to help evaluate their navigator programs against several core measures:

- Was the education offered by the navigator helpful?
- Was coordination of care timely?
- Did the support given by the navigator help reduce fears?
- How was the navigator's knowledge of disease and treatment options?
- Did the navigator share resources to help reduce barriers to care?

The NCCCP patient survey highlighted the reality that people are often unaware of navigators and the benefits their services can provide patients. Although many cancer centers offer patient navigation services, marketing campaigns do not spotlight them. Using information from the patient surveys, NCCCP sites began to direct navigation program marketing efforts, establish quality measure checks, understand patient educational needs, and streamline the referral process.

## Successful Outcomes

Looking back, the patient navigation programs at all NCCCP sites experienced success during the program's pilot phase. Quality of care was improved and physician support increased. Many of the navigators:

- Joined nationally recognized organizations, including the Academy of Oncology Nurse Navigators and the National Coalition of Oncology Nurse Navigators
- Participated in activities to advance the standard of care for patients
- Shared the benefits of nurse navigation.

Comprehensive navigation programs with appropriate staffing can help meet the needs of targeted, underserved populations by conducting outreach activities and providing services that will reduce healthcare disparities and increase access to care for disparate populations. 📌

---

*Jay R. Swanson, RN, BSN, OCN, is oncology nurse navigator at Saint Elizabeth Cancer Institute, Lincoln, Nebr. Thomas Asfeldt, RN, BAN, MBA, is director, Outpatient Cancer Services and Radiation Oncology and co-principal investigator for NCCCP site Sanford USD Medical Center in Sioux Falls, S.D. Carolyn Kalaskie, MS, is the co-director of the outreach group ANGEL*

*Network in Colorado Springs, Colo. Patricia Strusowski, MS, RN, is director, Cancer Care Management at Helen F. Graham Cancer Center, Newark, Del. Eileen Van Pelt, RN, OCN, was oncology nurse navigator at Saint Francis Cancer Center, Grand Island, Nebr. Rachel Oelmann, MBA, was NCCCP program coordinator, Sanford USD Medical Center, Sioux Falls, S.D. Dawn Parsons, RN, OCN, is clinical manager for Seton Cancer Screening and the Seton Cancer Care Team at University Medical Center Brackenridge, Austin, Tex. Maria Gonzalez, BS, is manager, Cancer Research at St. Joseph Hospital Center in Orange, Calif. Mitchell Berger, MD, MMM, CPE, FACP, is medical director and principal investigator for NCCCP site The Cancer Program of Our Lady of the Lake and Mary Bird Perkins Cancer Center, Baton Rouge, La.*

## References

<sup>1</sup>Wilcox B, Bruce SD. Patient navigation: A "win-win" for all involved. *Oncol Nurs Forum*. 2010;37(1): 21-25.

*The authors wish to acknowledge contributions by the NCCCP Pilot Principal Investigators during the creation of the NCCCP White Papers: Thomas Asfeldt, RN, BAN, MBA, and Maria Bell, MD, Sanford USD Medical Center; James Bearden, MD, Spartanburg Regional Hospital; Mitchell Berger, MD, Our Lady of the Lake Regional Medical Center; Richard Freeman, MD, Ascension Health; Jay Harness, MD, and Nancy Harris, MPA, St. Joseph Hospital/Orange; Mark Krasna, MD, Catholic Health Initiatives; Nicholas Petrelli, MD, Christiana Hospital; Thomas Purcell, MD, Billings Clinic; Andrew Salner, MD, Hartford Hospital; and H. A. Zaren, MD, FACS, St. Joseph's/Candler.*

*In addition, the authors would like to recognize the efforts of NCCCP program staff and NCI advisors: Brenda Adjei, EdD, MPA, NCI; Mary Anne Bright, RN, MN, NCI; Arnold Kaluzny, PhD, Sheps Center for Health Services Research, University of North Carolina, Chapel Hill, N.C.; and Donna M. O'Brien, MHA, Community Healthcare Strategies, LLC.*

This project has been funded in whole or in part with federal funds from the National Cancer Institute, National Institutes of Health, under Contract No. HHSN261200800001E. The content of this publication does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.