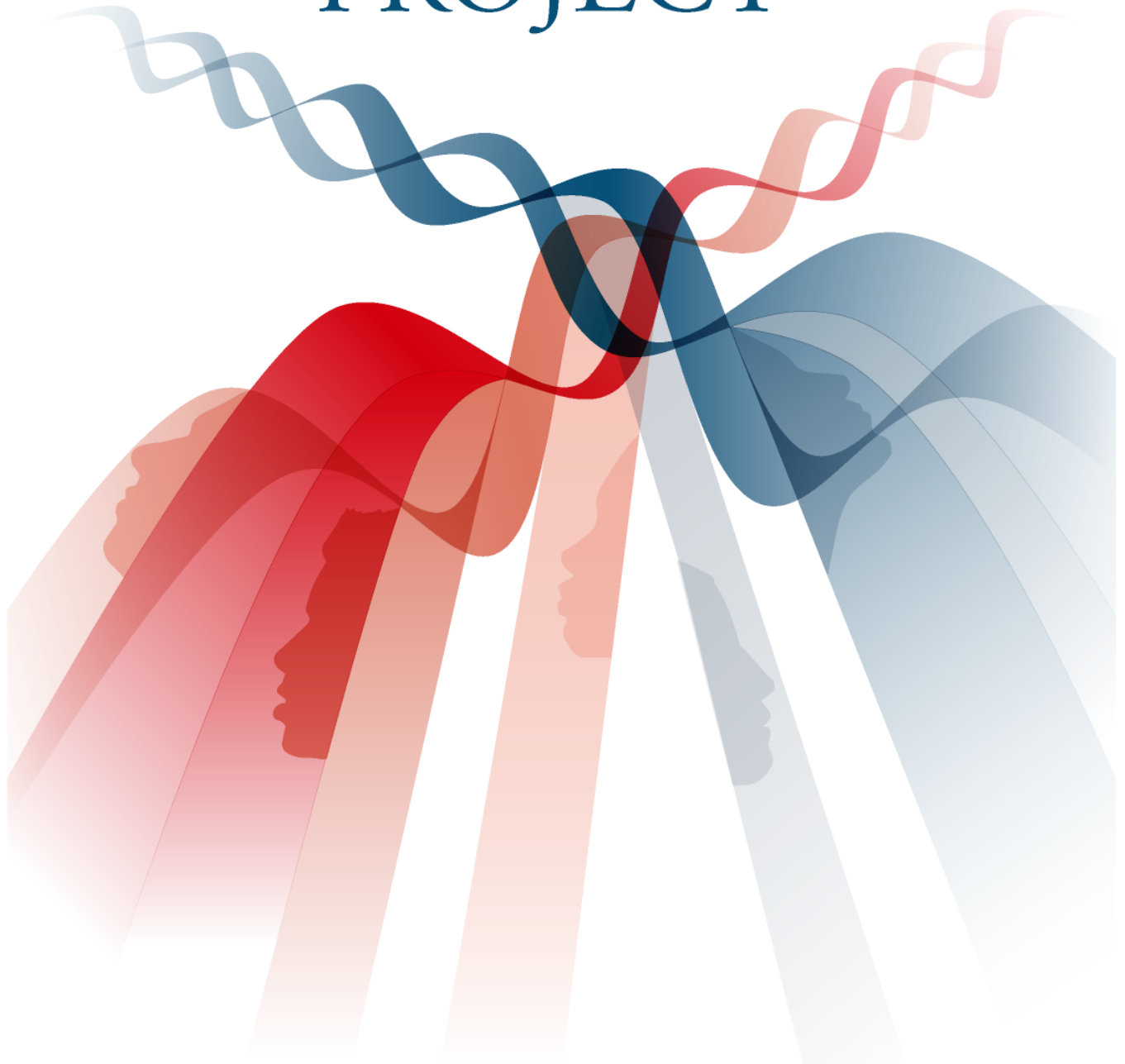


THE **DRA** Accelerating Disparity
Reducing Advances
PROJECT



Patient Navigator Program Overview

April 13, 2007 Report 07-02

Patient Navigator Overview

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Introduction

Patient navigation programs provide a very promising approach to reducing disparities for cancer and other diseases. It is a part of the consumer-navigation priority area for the DRA Project. This report provides an overview of a few of the more than 200 patient navigation programs as well as existing toolkits for patient navigators. Most of these programs focus on reducing disparities in cancer outcomes and have shown impressive results. The navigation concept has also spread to demonstration projects in preventative health. Among these programs there is a wide amount of variability around the types of navigators used, the method of outreach, the services provided and the communities they serve.

Patient navigators help patients and their families navigate the fragmented maze of doctors' offices, clinics, hospitals, out-patient centers, payment systems, support organizations and other components of the healthcare system. Services provided by patient navigators vary by program and the needs of the patient, but often include:

- Facilitating communication among patients, family members, survivors and healthcare providers.
- Coordinating care among providers.
- Arranging financial support and assisting with paperwork.
- Arranging transportation and child care.
- Ensuring that appropriate medical records are available at medical appointments.
- Facilitating follow-up appointments.
- Community outreach and building partnership with local agencies and groups.
- Ensuring access to clinical trials.¹

There is no one common definition of patient navigators and the profile of a patient navigator varies widely by program. Many use trained community health workers who may be full-time employees or volunteers. Community health workers have close ties to the local community and serve as important links between underserved communities and the healthcare system. They also possess the linguistic and cultural skills needed to connect with patients from underserved communities. Community health workers are also known as community health advisors, lay health advocates and *promotores de salud*.² Healthcare navigators include trained social workers, nurses and nurse practitioners as well as trained lay persons/volunteers. Some navigation programs also use a team based approach that combines community health workers with one or more professionals with experience in healthcare or social work. While there is no set education required for a patient navigator to be successful, a successful navigator should be:

- Compassionate, sensitive, culturally attuned to the people and community being served and able to communicate effectively.
- Knowledgeable about the environment and healthcare system.
- Connected with critical decision makers inside the system, especially financial decision makers.³

The adoption and use of patient navigation programs are showing significant momentum, but more evidence is needed for widespread adoption. The Harlem Cancer Education and Demonstration Project was the first indication of the promise of patient navigation in improving outcomes for underserved patients. Other community based patient navigation projects have expanded on this evidence base. However, the lack of a clear definition for patient navigators and patient navigator services has made it difficult to aggregate data across programs and establish best practices. To keep the momentum for patient navigation more rigorous studies are needed of the patient navigation role as well as program costs and benefits.⁴ Fortunately, a number of these rigorous studies are underway through projects such as the Cancer Health Disparities Patient Navigator Research Program and the Medicare Cancer Prevention and Treatment Demonstration for Racial and Ethnic Minorities.

Patient Navigator Programs

A survey conducted by the National Cancer Institute in 2003 found more than 200 cancer programs nationwide with some form of patient navigation. Most of these were funded by small grants from foundations.⁵ These programs vary widely in their approach to patient navigation. Many use workers from the communities they serve and are often cancer survivors themselves. Almost all provide some form of training although the length and the subject matter can vary significantly. The method of outreach and activities can vary significantly as well. Some navigators meet face to face while others use the phone or internet as the primary mode of contact. Below are some of the ongoing and completed patient navigation programs. Also included are two toolkits for patient navigators and champions wishing to start patient navigation programs in their own communities.

American Cancer Society

The ACS introduced the first patient navigator program for cancer at Harlem Hospital in 1990. Since then, the ACS continues to support patient navigator programs throughout the United States. In 2005, ACS formally launched the ACS Patient Navigator program. There are currently 60 American Cancer Society Patient Navigator program sites across the U.S. helping cancer patients, survivors and their caregivers navigate the cancer experience. In February of 2007, AstraZeneca provided a \$10 million gift to help expand the Patient Navigator program. The gift will allow ACS to open 50 new patient navigator sites over the next five years.⁶

ACS patient navigators are full-time employees that are nationally trained by ACS in collaboration with the navigators from the NCI Patient Navigation Research Program. ACS navigators also receive localized training and ongoing opportunities for collaboration. Many of the ACS navigators are concentrated in hospitals and clinics and treat a large number of medically underserved patients. They provide a range of services to patients from arranging transportation to providing information on financial assistance programs.

The Centers for Medicare and Medicaid Services (CMS)

In April of 2006, CMS awarded 4-year cooperative agreements to 6 demonstration sites through the Medicare Cancer Prevention and Treatment Demonstration for Racial and Ethnic Minorities. The demonstration project will provide patient navigation services to more than 13,000 minority Medicare fee-for-service beneficiaries. The project will use a randomized control design and will incorporate another 13,000 patients as control participants in the study. Researchers will study whether patient navigators improve care for minorities. The program will cost almost \$24 million and last four years. The table below provides more information on the 6 demonstration sites.

Table #2: CMS Navigation Sites

City/Region	Target Population	Partner	Program Size
Montana/Utah	American Indian	Huntsman Cancer Institute	1,940
Molokai, HI	Asian American & Pacific Islander	Molokai General Hospital	578
Harris County & Houston, Texas	Hispanic (Mexican American)	M D Anderson Cancer Center	3,600
Newark, NJ	Hispanic (Puerto Rican, Cuban)	New Jersey Medical School	1,384
Baltimore City, MD	African-American	John Hopkins University	3,074
Greater Detroit	African-American	Josephine Ford Cancer Center	3,050

The project will enroll participants with and without cancer. For those without cancer, the sites will offer patient navigator services to facilitate screening and diagnosis for breast, cervical, colorectal and prostate cancer. The sites will recruit participants with any of these cancers as well as lung cancer, for other navigator services including: assistance in scheduling appointments with culturally sensitive caregivers, providing education/information, providing transportation assistance, coordinating care among providers, arranging for translation/interpretation services, as well as providing other services to overcome the barriers encountered during cancer care.⁷

The patient navigators for the project are community health workers recruited from local communities and supervised by nurses or medical social workers. Training is done on site. Major evaluation questions for the project include:

- Did the demonstration reduce racial/ethnic disparities by improving screening rates, treatment completion rates, etc?
- Did the demonstration reduce Medicare spending (or at least not increase it)?
- Were beneficiaries and providers satisfied with the demonstration services?

National Cancer Institute/Center to Reduce Cancer Health Disparities (NCI/CRCHD)

Started in 2002, the Patient Navigator Program has three research projects to evaluate the efficacy and cost-effectiveness of patient navigation. The primary project, the Patient Navigator Research Program (PNRP), is providing five year funding to eight project sites looking at four types of cancer (breast, cervical, colorectal and prostate). A total of \$25 million in grants have been authorized for the eight project sites.⁸ A ninth

site, The Ohio Patient Navigator Research Project, is funded by the American Cancer Society. The table below provides more information on the nine project sites.

Table #1: NCI/CRCHD Navigation Sites

City/Region	Target Population	Cancer Type	Navigator Type	Location
Boston	Racial/Ethnic Minorities & Low Income	Breast & Cervical	Culturally Competent Navigators	Community Health Centers
Denver/Rocky Mountains	African American, Hispanic/Latino & Underserved	Breast, Colorectal, Prostate	Community Health Workers	Various Sites
Washington D.C.	African American, Hispanic/Latino & Underserved	Breast	Navigator/Peer Counselor Team	Various Sites
Tampa Region	African American, Hispanic/Latino & Migrant Worker	Breast & Colorectal	Lay Navigators	Community Health Centers
Northwest Portland Area	American Indian & Alaska Native	Breast, Cervical, Colorectal & Prostate	Nurse/Community Navigator Team	Tribal Communities
Chicago	African American & Hispanic/Latino	Breast, Cervical, Colorectal & Prostate	Nurse/Social Worker/Lay Navigator Team	VA & Health Center Clinics
Rochester	Racial/Ethnic Minorities & Low Income	Breast & Colorectal	Community Health Workers	Large Inner City Practices & Hospital Oncology Clinics
San Antonio	Hispanic/Latina	Breast & Cervical	Promotoras	Various Sites
Columbus, Cleveland & Cincinnati	Underserved	Breast, Cervical & Colorectal	Patient Navigator	Various Sites

More information available at <http://crchd.cancer.gov/pnp/pnpr-research-sites.html>

Each of the sites partners with local organizations to serve underserved populations such as racial/ethnic minorities, patients with lower socioeconomic status and patients in rural areas. Some of the research questions the principal investigators are exploring include:

- What is the impact of the type of navigator on success?
 - Volunteers vs. paid professionals?
 - The type of navigator (i.e. social worker, nurse, lay individual, community worker)
- Does the location of the navigator effect outcomes (i.e. inpatient or outpatient)?
- Does race/ethnicity or language matching improve outcomes?
- Does the type of navigator impact cost-effectiveness?⁹

The program runs centralized training for navigators involved with the program in collaboration with the American Cancer Society and local partners. The course lasts three full days and includes knowledge development on patient navigation and cancer; a practicum on patient assessment, barriers and resources; and skills development in research, communication and culture & diversity. NCI continues to fund patient

navigator pilot projects outside of the Patient Navigator Program. These pilot projects are aimed at American Indian, Hispanic/Latino, African American and rural underserved populations across the United States.

Clinical Directors Network

The Clinical Directors Network (CDN) is a not-for-profit network of primary care clinicians in Community/Migrant Health Centers. Last year, CDN published a randomized study of 1,413 women in a phone based patient navigation program designed to improve cancer screening. The women were regular patients at one of 11 community and migrant health centers in New York City. All the women were overdue for one or more cancer screening tests and most were from low-income neighborhoods (78% were enrolled in Medicaid). Women in the control group were contacted by trained care managers who encouraged them to receive screening, provide information on screening and provide assistance in arranging appointments and transportation. The women received an average of 4 calls. The care managers were provided with seven hours of training on screening, screening guidelines, techniques for motivational interviews and role-playing. Rates of screening for all three cancers (breast, cervical and colorectal) in the intervention group increased dramatically.¹⁰

Harlem Hospital Center

Started in 1990, the Harlem Cancer Education and Demonstration Project (HCEDP) is the first patient navigation program. The program addressed barriers that poor patients face in trying to obtain follow up services after suspicious findings. The project showed that 85.7% of patients that receive navigation after suspicious findings from a breast examination or mammogram received recommended breast biopsies versus 56.6% of non-navigated patients.¹¹ The study also showed improvements in 5 year survival rates for patients during the five years of the navigation program compared to patients in an earlier period. However, multiple factors likely affected survival rates including advances in diagnostic and therapeutic modalities.¹² Harlem Hospital Center serves a predominantly poor, urban, African American population.

Long Island College Hospital

In early 2000, Long Island College Hospital began a Breast Health Navigation (BHN) Program at its Othmer Cancer Center. Located in Brooklyn, the Hospital serves a diverse community of African-Americans, Latinos and persons of Indian, Italian, Jewish Orthodox, Russian Orthodox, West Indian, Haitian, and Arabic descent. The BHN Program built on the Harlem Cancer Education and Demonstration Project, but added a few new elements to serve its unique community and to facilitate the evaluation of the program. For example, the program:

- Incorporated a component on data collection so that outcomes and costs savings could be measured and evaluated,
- Added a problem-solving or algorithm process, and
- Expanded the role of the breast health navigators to enable them to track the patient throughout the breast cancer trajectory (from screening through diagnosis, surgery, therapy and recovery)¹³

To date, the BHN Program has been successful in improving outcomes for patients. For example, the breast cancer support group has experienced a 20% increase in attendance. Patient satisfaction has increased and the majority of patients in the BHN Program report their experience as very pleasant or satisfactory. Average length of stay has also been reduced by one day due to a decrease in delays in obtaining rehabilitation consults. The BHN Program also helped identify systematic problems in scheduling, patient follow-up and logistics. Improvements in these areas, including new algorithms for patient navigators, have seen system wide improvements. When the program started only 25% of patients had follow-up visits scheduled before leaving the hospital. Now, ninety-nine percent of all clinic patients have follow up appointments.¹⁴

Men as Navigators for Health

The Men as Navigators for Health program is a CDC funded project designed to explore the use of men of color as lay health navigators. The program is a participatory research project designed to improve chronic disease and sexual health outcomes for African American and Latino men in North Carolina. The goals of the project are:

- Translate, disseminate, and evaluate the health impact of a lay health advisor among men of color.
- Implement and evaluate a technical assistance model for developing long-term, culturally competent systems of care; and
- Develop and evaluate a surveillance system of methods and indicators for local health departments to monitor health status, health care utilization, related psychosocial factors among individuals, and cultural competence of health care systems and other organizations.¹⁵

National Association of Social Workers and C-Change

This year C-Change and the National Association of Social Workers have partnered to produce a patient navigator toolkit. The purpose of the toolkit is to market the concept of patient navigation. More information on the toolkit will be available at the April 11th DRA Partners Meeting. The toolkit will be released in October 2007.

Nova Scotia

In 2002, Nova Scotia began a patient navigator program, The Nova Scotia Breast Screening Program, for breast cancer in three early adopter sites. Patients who received navigation had significantly reduced time intervals between mammography and core breast biopsy for those patients with suspicious breast findings. In 2000, patients who were referred by their physician for a biopsy after diagnostic imaging saw a significant decrease in wait times after patient navigation was introduced. The wait time improved 30% from an average of 20 days to 14 days.¹⁶

Cancer Care Nova Scotia also performed a peer review program on the impact of patient navigation for cancer care on caregivers, families and related health professionals. Review of the program found that patient navigators significantly benefited cancer patients and their families in dealing with the emotional turmoil, informational needs and logistical challenges associated with having cancer. Patient

Navigation also resulted in more efficient use of clinical time of physicians and facilitated the more appropriate use of community health professionals.¹⁷

Pfizer

Pfizer in cooperation with the Healthcare Association of New York and prominent navigation experts have recently developed a multimedia toolkit for patient navigators. Experts consulted in designing the toolkit include Harold Freeman, Hannah Linden, Amelie Ramirez and Lillie Shockney, among others. Harold Freeman is the Medical Director of The Ralph Lauren Center for Cancer Care and Prevention in New York City. Freeman also established the first patient navigation program in 1990 at Harlem Hospital and, as director of the NCI/Center to Reduce Cancer Health Disparities, he oversaw the development of the NCI/CRCHD navigator program.

The toolkit, Cancer Care: Guiding Patients to Quality Outcomes includes resources for both program champions who want to initiate and support patient navigation programs and patient navigators. It includes manuals for healthcare personnel who want to champion patient navigation programs in their own organizations. Another manual provides information on the navigation function and how to guide patients through the healthcare system. Two other manuals provide information on breast and colorectal cancer. The Patient Navigation in Cancer Care [website](#) provides other resources for navigators including a directory of patient navigators, best practices, expert commentary and a resource library.

Comparison Chart

Patient Navigation Program Overview

Name	Target Population	Sites	Focus Area	Navigator Type
ACS Patient Navigator Program	Mostly Medically Underserved	Over 50 sites	Cancer (various types)	Trained Patient Navigators
Medicare Cancer Prevention and Treatment Demonstration for Racial and Ethnic Minorities	Minority Medicare fee-for service beneficiaries	6 sites	Breast, Cervical, Colorectal & Prostate Cancer	Community Health Workers Supervised by Nurses or Medical Social Workers
CRCHD Patient Navigator Research Program	Racial/Ethnic Minorities, Low Income & Underserved	9 sites	Breast, Cervical, Colorectal & Prostate Cancer	Various (see table 2)
Clinical Directors Network	Underserved Women	11 sites	Screening for Breast Cancer	Trained Care Managers
Harlem Cancer Education and Demonstration Project	Mostly Underserved African American	1 site	Breast Cancer	Trained Patient Navigators
Breast Health Navigation Project	Various	1 site	Breast Cancer	Trained Patient Navigators
Men as Navigators for Health	African American & Latino Men	1 site	Chronic Disease & Sexual Health	Lay Health Advisor
NASW Collaborating to Conquer Cancer Toolkit	Organizations & Communities	Online	Cancer (various types)	Toolkit
Nova Scotia Breast Screening Program	Various	3 sites	Breast Cancer	Trained Patient Navigators
Cancer Care: Guiding Patients to Quality Outcomes	Patient Navigators & Program Champions	Online	Cancer (various types)	Toolkit

End Notes

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