

# Longitudinal Network Patient Navigation

## Development of a city-wide integrative model to reduce breast cancer disparities in Washington, D.C.

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### In Brief

The George Washington University Cancer Institute (GWCI) is a comprehensive academic cancer center whose mission includes understanding and eliminating cancer disparities. To combat breast cancer disparities in Washington, D.C., GWCI instituted the D.C. Citywide Patient Navigation Research Program (DC-PNRP)—one of nine national PNRP sites funded by the National Cancer Institute (NCI) and the American Cancer Society to evaluate the effectiveness of patient navigation. The Washington, D.C., site is unique in its “network navigation” approach.

Here’s how our innovative model works. Navigators from a broad partnership of unaffiliated clinical and community sites are trained to work collaboratively within a city-wide network to enroll patients in the study and assure each patient receives timely, quality care. In the process, we encountered and overcame a number of administrative, operational, and IRB-related difficulties inherent to a complex network of non-affiliates. Three strategies help us enhance care coordination and assure appropriate referral strategies between community outreach, screening, and treatment sites: 1) frequent staff training, 2) efforts that promote increased communication between navigators, and 3) a method for sharing information about community resources.

Our experience suggests that navigation services positioned at various points in the healthcare system and linked to one another through citywide networked systems of care coordination may increase patient satisfaction and improve adherence to lifesaving treatments. After implementing the DC-PNRP, we broadened the original treatment-oriented navigation model to create a “longitudinal navigation” paradigm that follows the patient from outreach through survivorship.

Over the last 10 years, breast cancer mortality rates for African-American women living in the nation’s capital have dramatically improved. Increased screenings and advances in treatment have had significant impact, reducing the mortality rates from 49.8 (per 100,000) in 1995 to 31.5 in 2005.<sup>1</sup> Despite these improvements, disparities between population groups persist and in 2005, mortality rates among white women (20.7) remained markedly lower than those of their local African-American counterparts. Mortality rates from breast cancer for Latinas in the Washington, D.C., metro area (DC) are unavailable, but given the

growth in this population, the actual numbers of deaths is expected to rise.<sup>2</sup>

Local rates for breast cancer incidence (cases per 100,000 population per year) are also higher than the national average among white (145 vs. 126), African-American (124 vs. 112), and Hispanic (103 vs. 89) women. Because of these higher-than-average incidence rates and persistent disparities in mortality rates, increased efforts to identify and overcome barriers to care have grown in recent years. In 2006 almost 82 percent of all women living in DC over 40 years of age report having a mammogram during the last two years.<sup>1</sup>

In 2001 a publicly funded safety-net insurance program for low-income DC residents was implemented and has helped to lower the number of uninsured (9 percent compared to 15 percent nationally), but among these individuals, the burden falls disproportionately on African Americans (56 percent) and Hispanics (23 percent).<sup>3,4</sup> A 2008 report on healthcare access in DC found that mammography screenings for uninsured versus insured women over age 50 demonstrated significant differences (65 percent vs. 85.6 percent). In Wards 7 and 8, a geographically isolated quadrant of DC where rates of concentrated poverty, low educational achievement, and uninsured residents are the highest, screening continues to lag behind other wards in the city. Until November 2008, only one approved, functional mammography facility existed in these neighborhoods.<sup>5</sup> However, this facility is northwest of the Anacostia River, the geographic and psychosocial barrier that isolates this quadrant of DC with the highest poverty rates. Studies have shown a direct correlation for statewide mammography rates with the proximity of facilities, indicating that the rate of screening depends on availability of screening services.<sup>6</sup>

### The Importance of Access to Care

While most attempts to reduce cancer disparities focus on screening, much of this problem is also attributable to disparities in access to optimal treatment.<sup>7-11</sup> Many of the city’s hospitals and cancer centers are clustered close to each other and geographically remote from high-poverty areas, which magnifies the perception of concentrated poverty and further marginalizes the economically disadvantaged. Among the poor, many people also have language barriers and are unaware that they qualify for funds or healthcare services.<sup>10-14</sup> In DC the following major negative factors influencing cancer control have been identified:<sup>15</sup>

- Lack of a medical “home” (inadequate primary care)
- Difficulties in accessing screening services
- Health information and education deficits
- A fragmented health insurance system
- A large proportion of uninsured or underinsured
- High poverty rates



- Low literacy rates
- Fear and medical mistrust issues
- Cultural and language barriers
- Misconceptions and stigma about cancer
- A healthcare labyrinth (a complex healthcare system).

Patient access to care has many levels and includes entrance to the healthcare system and being able to negotiate and communicate with providers within the system. For example, low-income patients who receive screening services through the CDC-funded safety-net program for uninsured women known as Project WISH (Women Into Staying Healthy) have to be re-enrolled in DC Medicaid if a positive cancer diagnosis is made and treatment is required because Project WISH only covers screening and diagnostic mammograms.<sup>16</sup> The process is overwhelming and often complicated by the woman's lack of experience in accessing the services needed to increase the chances of survivorship. This situation exemplifies the growing national need for healthcare professionals who are trained to help patients overcome barriers and who can also become clinical advocates for these patients.

### The GWCI Response

In response to a request for applications (RFA) issued by the National Cancer Institute in 2004, GWCI organized a planning group of collaborative partners from the city's major medical centers and community groups. The goal of this planning group was two-fold—to develop a city-wide breast cancer navigation program and a proposal for studying the effectiveness of navigation in reducing cancer disparities in DC. Initially, four of the city's major medical institutions decided to collaborate with two community partners in an unprecedented consortium to create a city-wide patient navigation program to assist African-American and Latina women to navigate the healthcare system. From the outset, our navigation program was designed to create a system of “network navigation” by joining together unaffiliated institutions with the common goal of reducing DC's large disparities in breast cancer incidence and mortality. Table 1 on page 30 lists all the organizations that participated in the DC-PNRP since its inception.

In 2005 the NCI's Center to Reduce Cancer Health Disparities, together with the American Cancer Society (ACS), awarded five-year grants to empirically evaluate the effectiveness of patient navigation to nine sites across the United States, including the DC-PNRP. To narrow the study parameters, the PNRP navigation model initiates navigation at the point of suspicious finding with follow-up through diagnostic resolution for non-cancers and through the end of treatment for cancers (see Figure 1a, page 32).

Each of the nine national PNRP sites enrolls patients

with suspicious breast findings or breast cancer; some sites also enroll patients with either colorectal, prostate, or cervical cancers—cancer sites selected for patient navigation services because of the existence of reasonable screening tests associated with each disease such that early detection is possible and can lead to more favorable outcomes. Each PNRP site is also focused on delivering patient navigation services to one or more minority and/or disadvantaged populations. The DC-PNRP focused on low-income groups, African Americans, and Hispanics.

The DC-PNRP is evaluating breast cancer because each partner institute had an organized breast health program and the clinical definitions for suspicious findings and diagnosis across institutions were more similar for breast cancer than any other cancer. It is important to note that these medical centers and community groups had rarely, if ever, worked together on any collaborative clinical or community research effort. This new collaboration was facilitated by the recently created DC Cancer Consortium (DCCC)—a voluntary group of cancer healthcare stakeholders (academic, government, private, and community-based) who together developed and are implementing a Cancer Control Plan for the District of Columbia.<sup>15</sup>

The DC-PNRP planning group worked with community leaders from DCCC who later became part of the DC-PNRP Community Advisory Panel (CAP). The CAP was constructed during the initial planning year. Representatives from community health advocacy groups, representing underserved populations and people of low socioeconomic status in the DC metro area were included on the CAP. The CAP meets at least once per year to review project accomplishments and advise the principal investigator and DC-PNRP staff on upcoming activities.

### Original Study Design

Within the DC-PNRP system of network navigation, we planned to evaluate two types of navigation in a randomized trial. The first type was standard-structural navigation to address access-related barriers. These might include barriers related to finances, transportation, information, communication, child/elder care, employment, housing, language and culture, and physical co-morbidities. The second type was enhanced or “integrative” navigation, consisting of standard-structural navigation plus ethnically and linguistically competent peer counseling to address psychosocial barriers, attitudes, perceptions, beliefs, fear and medical mistrust, social support, and mental health co-morbidities.

Subjects were randomly assigned to one of the two types of navigation and we evaluated effectiveness by examining differences in the length of time from abnormal finding to diagnosis and, if needed, to treatment.

After the one-year Pre-Phase was completed in 2006,

**Table 1. Participating Members of the DC-PNRP Navigation Network**

<b>Recruitment Intake Site</b>	<b>Group(s) to Whom Services are Provided</b>	<b>Current Status</b>
The George Washington University Cancer Institute in affiliation with GWU Hospital, GWU Medical Center, and GWU Medical Faculty Associates and Mammovan	Controls, including low-income women	Ongoing recruitment
The Preventorium at Washington Hospital Center	Navigated patients, mainly Latinas	Ongoing recruitment
Howard University Cancer Center	Navigated and control patients, mainly African Americans	Ongoing recruitment
Capital Breast Cancer Center in affiliation with Lombardi Cancer Center of Georgetown University	Navigated patients, mainly African Americans and Latinas	Ongoing recruitment
Nueva Vida, a community health group	Navigated patients, mainly Latinas	Ongoing recruitment
Center for Breast Health at Washington Hospital Center	Navigated and control patients, mainly low-income Latinas and African Americans	Ongoing recruitment
Providence Hospital	Navigated and control patients, mainly African Americans	Ongoing recruitment
Unity Health Care, a local system of federally funded community health centers	Navigated and control patients, mainly low-income, uninsured Latinas and African Americans	Ongoing recruitment
DC Department of Health – Project WISH (Women Into Staying Healthy) Program that provides free cancer education, screening, and diagnostic services	Controls, mainly low-income and uninsured	Ongoing recruitment
DC Area Health Education Center, a community health group that planned to provide enhanced navigation	Navigated patients, mainly African Americans	Discontinued due to change in study design
Breast Cancer Resource Committee, a community health group that planned to provide enhanced navigation	Navigated patients, mainly African Americans	Organization disbanded

we entered into a three-to-four year Implementation Phase to deploy the study procedures. The Implementation Phase involved:

- Training navigators in all aspects of the navigation and data collection protocols
- Accruing women at the recruitment intake sites
- Developing and using a computer-based data collection and tracking system
- Implementing standardized concrete and enhanced-integrative navigation services.

A special emphasis during local training sessions continues to include role-playing and ways to strengthen the network of navigators through referrals, communication, and resource sharing. The final six months of the grant period has been set aside for data analysis. The grant will end on August 31, 2010.

### **Adapting to Change and Challenges**

One of the first challenges confronting DC-PNRP at the time of the grant award in 2005, was identifying a replacement community group for one of the project's identified recruitment intake sites. After more than 15 years of service to DC's African-American community, the Breast Cancer Research Committee unexpectedly closed its doors. The

District of Columbia Area Health Education Center was selected as a replacement, specifically the site located within what was then the Greater Southeast Community Hospital.

For DC-PNRP, the most significant challenge occurred at the start of the Implementation Phase in January 2007 when it became clear that the lines of distinction between standard-structural navigation and enhanced-integrative navigation were becoming increasingly blurred. From 2004 to 2007, the concept of patient navigation swept the country, making navigation and sometimes even high-level navigation that included psychosocial components, routine standard of care in many places, including several of the DC-PNRP recruitment intake sites. With many national and local foundations funding demonstration projects in the DC metro area, many of the recruitment intake sites began to routinely offer what DC-PNRP previously defined as enhanced-integrative navigation as their standard of care—a dramatic departure from the situation in 2004 when the grant application was written. The rapid dissemination of navigation services throughout DC, including more experienced, trained patient navigators, providing more services for underserved DC women, was celebrated; however, this success caused unanticipated problems for DC-PNRP in terms of maintaining a valid study design to empirically assess the effectiveness of patient navigation.

**Table 2. DC-PNRP Program Components, Challenges, and Outcomes**

<b>Program Component</b>	<b>Challenge or Obstacle</b>	<b>Outcome</b>
Address disparities in breast cancer mortality between whites and minorities in DC.	Access to care hindered by lack of comprehensive services at facilities frequented by underserved women.	Network patient navigation model developed to assure patients are navigated throughout their breast cancer screening, diagnosis, and treatment periods.
Randomized controlled trial of subjects receiving patient navigation versus non-navigated controls.	Concern about ethics of a program that limits services to only one group.	Developed randomized trial examining two-tiered navigation: standard-structural (addresses access-related barriers) versus enhanced-integrative (includes psycho-social component).
Include community health groups focused on providing enhanced-integrative navigation—one for Latinas and one for African Americans.	The Breast Cancer Resource Committee, an African-American community group, was disbanded.	Identified new African-American community health group, District of Columbia Area Health Education Center, to provide enhanced-integrative navigation.
Original study design compared standard-structural navigation to enhanced-integrative navigation.	Enhanced patient navigation became standard of care at all recruitment intake sites.	Revised study design to compare patient navigation to concurrent, records-based state-of-care controls requiring re-structuring of recruitment intake sites to provide case and/or control subjects.
Establish city-wide DC-PNRP Grant awarded to the George Washington University Cancer Institute.	Several unaffiliated sites are participating.	Required development of sub-contracts, budgets, and adaptation of data collection procedures to adhere to administrative structure at each site.
Need to recruit navigated breast patients.	Criteria for inclusion as a recruitment intake site included existence of breast care center or infrastructure and desire to develop a breast navigation program and identification of individual to serve as co-investigator.	Identified several sites fulfilling inclusion criteria (see Table 1, page 30).
Separate institutional review boards (IRBs) at hospital and clinical participating sites; no IRB at community sites.	Each IRB had its own requirements, expectations, and levels of risk avoidance; community groups needed IRB affiliation.	Obtained approval from each IRB at hospital and clinical sites; GWU Medical Center IRB acted as IRB of record for community sites.

DC-PNRP and NCI staff met several times to discuss the change in navigation services available in DC and its impact on the project. It was agreed that all DC-PNRP navigation services would have to be consolidated into one arm because “standard-structural navigation” and “enhanced-integrative navigation” were no longer easily distinguishable in the DC area. This decision meant that the District of Columbia Area Health Education Center could no longer serve as a study recruitment intake site since its services were focused mainly on outreach activities and counseling. However, for Nueva Vida the situation was somewhat different. Nueva Vida was very well known within DC’s Hispanic community and was often the first place Latinas turned to when they found a breast lump or obtained a suspicious finding from a physician or screening center. Therefore, we decided to use Nueva Vida as a recruitment intake site for DC-PNRP even though it does not offer any clinical services. Table 1 on page 30 lists both current and former participating intake sites.

Consolidating navigation into one arm meant that DC-PNRP had to identify a new control group to compare to the navigated group. In addition to the high-level navigation services available at the recruitment intake stations, multiple navigation “demonstration projects” were being tested in DC, making it extremely difficult to identify one or more sites where patients with suspicious findings were being diagnosed and treated without any navigation services. In other words, we could not identify a verifiably uncontaminated control group. The solution: DC-PNRP implemented a records-based control group of woman who did not receive PNRP-related navigation services. Sources for a records-based population of controls include several city-wide screening programs for which time periods could be identified where patient navigation was not available.

Additionally, we identify women from records at the recruitment intake sites for the period just prior to the onset of navigation services. These women are identified through hospital tumor registries and outpatient and inpatient medi-



cal records at each recruitment intake site. However, recruitment intake sites that have offered navigation services since their inception, such as Nueva Vida, Preventorium, and Capital Breast Care Center, are not able to provide controls for the study.

Table 2 on page 31 identifies original DC-PNRP program components or plans, along with subsequent challenges and outcomes. Beginning in Pre-Phase, DC-PNRP staff from all recruitment intake sites met at least monthly to comment on the overall data collection and navigation protocols and provide input on community developments relevant to the program. Also during the Pre-Phase, we established an inter-institutional tracking and data entry system to cover patients from the time of referral to treatment resolution. During the monthly DC-PNRP staff meetings, we developed a “scope of practice” that identified job responsibilities and job descriptions for the navigators, along with provisions for clinical and/or administrative supervision, and mentoring with senior staff. DC-PNRP navigators have a wide array of backgrounds, with most having college degrees and several with many years of navigation experience.

### Process and Data Collection

At any of the recruitment intake sites, women identified with a suspicious breast finding are encouraged to enroll in the study provided they do not fit into one of the exclusion categories established by the national subcommittee:

- Age under 18 years
- Institutionalized
- Cognitively impaired
- Currently pregnant
- Previously navigated for cancer
- Prior cancer diagnosis more than five years ago.

Navigator training is part of the DC-PNRP. In addition to this training, DC-PNRP navigators are trained in enrollment techniques. Most navigators were hired as part of the PNRP, while others were already employees of their respective organizations—although not necessarily as navigators. All navigators associated with national PNRPs received training at several ACS-sponsored conferences. GWCI also provides additional navigator training through its Center for the Advancement of Cancer Survivorship, Navigation, and Policy.

Patients who agree to enroll in the study are asked to sign a consent form. Several recruitment intake sites have received

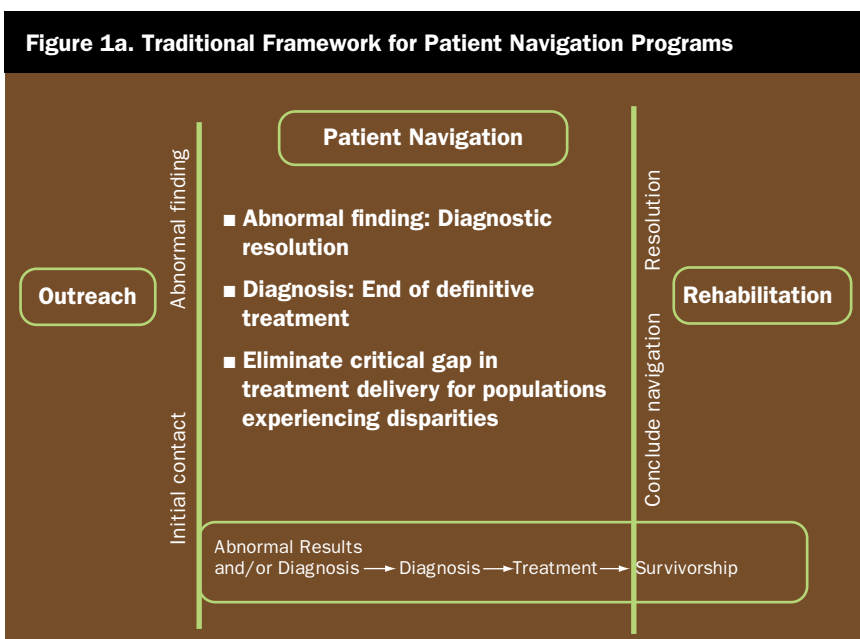


Figure 1a. Traditional approach to patient navigation developed by Harold Freeman, MD, and implemented in the Patient Navigation Research Program (PNRP) by the NCI’s Center to Reduce Cancer Health Disparities. It assures that patients are navigated beginning at suspicious finding, through diagnostic resolution, and, if needed, through treatment.

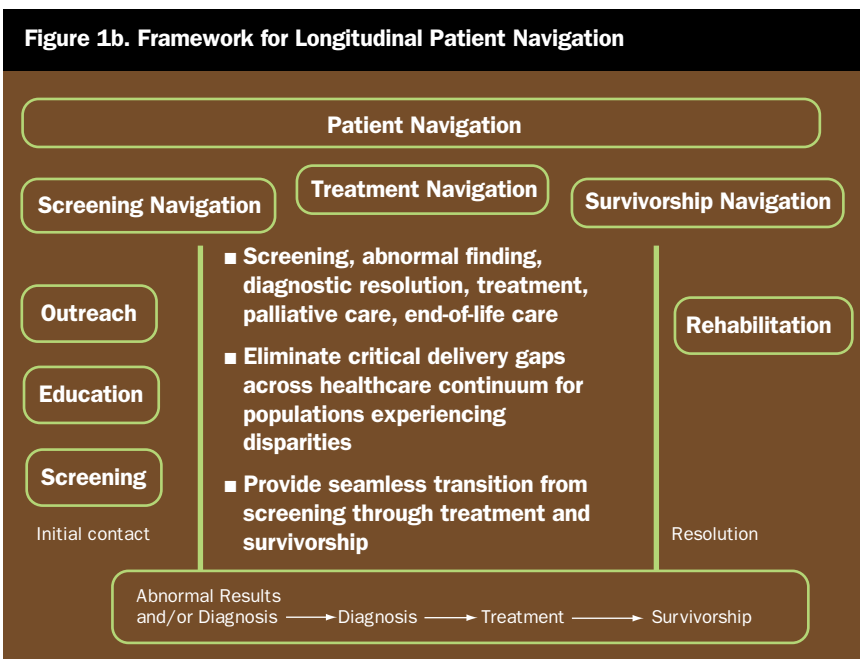
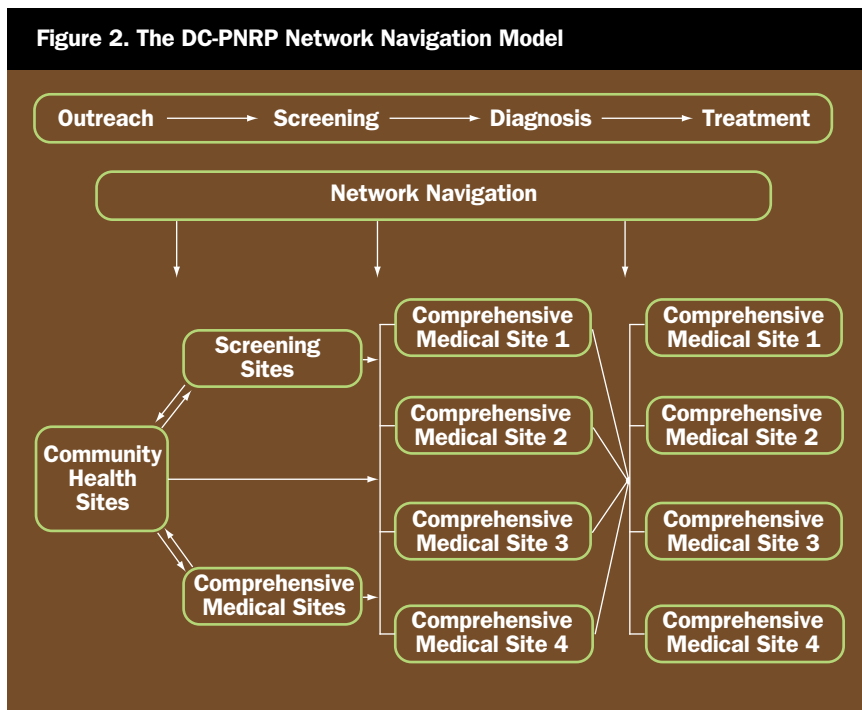


Figure 1b: The George Washington University Cancer Institute approach assures that patients are navigated beginning at outreach or screening, through diagnostic resolution, and, if needed, through treatment and well into survivorship.

permission from their respective IRBs to use verbal consent over the telephone. All navigated patients sign informed consent documents approved by one or more IRBs. Data on controls is solely record-based, using de-identified data; therefore, informed consent was waived by IRB.

Following the informed consent procedure, women are asked to complete the baseline questionnaire, either in-

**Figure 2. The DC-PNRP Network Navigation Model**



**Figure 2. Outreach, screening, diagnosis, and treatment are the phases in the breast cancer healthcare process. During outreach, community health sites navigate patients to screening sites and comprehensive medical sites that provide screening services. Patients identified at community health sites are then navigated to comprehensive medical sites for diagnostic resolution and, if needed, treatment.**

person or over the telephone. This questionnaire covers:

- Socio-demographics
- Family history of cancer
- Medical history
- Information-seeking style
- Acculturation
- Communication preferences
- Medical mistrust
- Perceptions of discrimination.

The latter items are factors that may moderate the effects of the intervention.

Immediately following diagnostic resolution, women are asked to complete the post-diagnostic questionnaire, which includes two validated instruments: CASE (the Communication Attitudinal Self-efficacy Scale) and the IES (the Impact of Events Scale). These instruments assess coping style, distress, and anxiety—additional factors that may moderate the effects of the intervention. For women diagnosed with cancer, the post-treatment questionnaire is administered three months following the initiation of treatment. It is similar to the post-diagnostic questionnaire and uses the CASE-Cancer version of that scale. GWCI research staff administers a satisfaction questionnaire at the post-diagnostic and post-treatment initiation time periods to assess the patient's level of satisfaction with her care generally, and with the navigation services in particular.

Navigators also complete several abstraction forms using data from the patient's medical records to obtain diagnostic and treatment information. Patients are followed through diagnostic resolution for non-cancer diagnoses and through

the treatment phase for cancer diagnoses (see Figure 1a, page 32).

After a slower than anticipated enrollment rate early in the program, rates have now accelerated. DC-PNRP expects to enroll 1,000 to 1,200 navigated patients, with a matching number of concurrent, records-based controls. The updated study hypotheses are that DC-PNRP's enhanced-integrative patient navigation services will: 1) decrease the time between suspicious finding and diagnostic resolution compared to non-navigated controls; and 2) decrease the time between diagnosis and initiation of treatment compared to non-navigated controls.

### GWCI's Network Navigation Model

DC-PNRP's system of network navigation functions at various unaffiliated recruitment intake sites across Washington, D.C. Navigators work collaboratively, with many patients being "networked"—identified with a suspicious finding at one site and diagnostically confirmed in another and/or treated at another site—to cooperatively enroll patients in the research program. Originally established for the research program to serve a low-income, ethnically diverse population of DC women, this network

of patient navigators is now a thriving community focused on sustainability.

Figure 2 above illustrates DC-PNRP's network navigation model. Patients with suspicious breast findings are identified at a community health site (clinical breast exam), a screening site (clinical breast exam and mammography), or a site offering comprehensive clinical services (screening, diagnosis, and/or treatment). With respect to the research program and data collection, patients are enrolled at the point of suspicious finding and followed through the end of treatment. However, navigators at recruitment intake sites that do not offer diagnostic and/or treatment services often function as "screening navigators" and refer patients to navigators at one of the sites with diagnostic and/or treatment services. Navigators from all DC-PNRP sites are thoroughly familiar with one another and knowledgeable regarding the services offered by other sites.

This familiarity developed over time through monthly meetings and webinars to discuss common problems and solutions. We created a contact list with all DC-PNRP team members' names, phone numbers, and email addresses. Additionally, a navigator email listserve is used to facilitate rapid communication between navigators and between navigators and the GWCI coordinating center. At this point, navigators know one another very well and frequently call each other about particular patients requiring services at another site.

Frequent communication among navigators assures that patients are not enrolled in the study more than once and that there is continued oversight of each patient's needs. Anecdotal reports suggest that the navigator network has improved the

coordination of services related to breast cancer screening, diagnosis, and treatment for low-income women in DC.

Although DC-PNRP is principally an NCI-funded research program with very defined and relatively narrow endpoints, our experience facilitated the formation of a navigation framework with several unique features. DC-PNRP's original study design comparing enhanced-integrative navigation to standard-structural navigation, together with DC's dominant minority population and extensive ethnic diversity, prompted city-wide attention to the need for navigation services to deal effectively with psychosocial issues such as fear, coping styles, medical mistrust, acculturation, communication preferences, and perceptions of discrimination. DC-PNRP navigators are trained in these areas, in addition to the more standard approach of helping overcome structural barriers, such as lack of transportation, lack of adequate insurance, and lack of knowledge of how and where to obtain optimal health care. DC-PNRP is simultaneously collecting data and conducting research on the effectiveness of these interventions.

As we developed DC-PNRP's system of network navigation, we encountered and overcame a number of challenges and/or obstacles (see Table 2, page 31). Despite these issues, we were able to train patient navigators from unaffiliated sites to work collaboratively and proactively to:

- Increase screening rates
- Reduce the time between identification of suspicious finding to diagnostic resolution
- Reduce the time between diagnosis and treatment initiation.

Collaborative working relationships, commitment to quality patient care, and advocating for timely healthcare access are the three overarching principles of network navigation. Monthly meetings and frequent training sessions allow navigators to share resources, review data collection and subject recruitment procedures, and evaluate referral strategies. In the event that further diagnostic services are needed, navigators at screening sites facilitate the hand-off of patients to navigators working at treatment sites. The patient's new navigators continue to work closely with her to provide support through subsequent appointments and ensure appropriate services are received. This integrative approach assures longitudinal navigation coverage for the patient from point of suspicious finding through treatment and into survivorship.

Under DC-PNRP's network navigation model, navigators have successfully minimized barriers to care and facilitated timely access to treatment.

Referral patterns for navigated patients have been tracked to identify service delivery needs, emerging inequities in the distribution of service, and untapped resources to share with patient navigators serving a large number of uninsured patients. Patients attending any of our recruitment intake sites may be from Washington, D.C., or the nearby Maryland or Virginia suburbs. Due to the unique geographic landscape of the metropolitan Washington, D.C., region, a patient's state of residence can offer unique opportunities or challenges for the navigators. When an uninsured patient is diagnosed with a malignancy, she may find more comprehensive treatment available through a pro-bono treatment program that is unique to the State of Virginia. In fact, the navigators often end up creating a quilt of stitched together services for an uninsured

patient that include radiation in Virginia, chemotherapy in Maryland, and oncology services in the District. This scenario is far from optimal and navigators actively seek to reduce the fragmentation of services by working together when barriers present themselves.

By tracking these referral patterns, navigators are able to update the information when funding for a particular program is reduced or eliminated, or when programs with new funding sources are created. Navigators may also be able to communicate to local funders and community advisory boards about emerging inequities (i.e., providers that cease to accept D.C. Medicaid) that threaten to undermine recent progress achieved through the patient navigator program. The intra-network communication network between navigators facilitates a continuity of care that is rare in our health system today. The initial relationship between patient and navigator is unique and most navigators follow their patients throughout the system, even while introducing the patient to the other navigators at other networked care sites.

Our network navigation model makes the DC-PNRP unique among all PNRP sites across the country. It represents an innovative and creative way to address barriers to access and the underlying fragmentation of services that exist for low-income women with no insurance or those enrolled in publicly funded insurance programs. At this stage of the program, study investigators have identified factors that enhance an effective navigator network. Frequent staff training, action plans developed by the navigators themselves to promote effective communication networks, and information sharing about community resources have been implemented to enhance care coordination. This research program will contribute to the growing body of evidence<sup>17</sup> that suggests navigation services are a unique and effective strategy to reducing cancer disparities.

### Longitudinal Navigation

The original navigation model developed by Freeman et al. in 1995 focused on navigating patients from abnormal or suspicious findings to the onset of treatment. This model was likely the result of a high demand for navigation services emanating from physicians, tumor registry staff, and screening clinic staff, and a limited navigation staff. This model was also heavily influenced by limited resources and the need to demonstrate cost effectiveness and economic feasibility of navigation services.

As the coordinating center for DC-PNRP, GWCI has developed navigation services to operate in concert with its Cancer Prevention and Control, Cancer Education and Outreach, and Cancer Survivorship Programs. Through an outreach program called *Community by Community Cancer Control Campaign*, with congregational, workplace, and neighborhood cancer wellness initiatives, GWCI outreach specialists have gained extensive experience in culturally relevant community-based education and screening. Through these programs, we have learned that the same barriers that affect access to treatment also interfere with access to, and utilization of, screening programs. Our findings suggest that a form of navigation we call "screening navigation" will help overcome these barriers when integrated longitudinally with outreach, education, and diagnostic services. Likewise, the barriers that underlie treatment disparities also contribute to disparities in accessing appropriate survivorship services, suggesting that "survivorship navigation" integrated longi-



tudinally with both treatment navigation and, when necessary, palliative care and end-of-life-care, may overcome these barriers and facilitate the often stressful period of transition from active care.

To address these challenges GWCI has developed the concept of “longitudinal navigation,” or navigation integrated across the full healthcare continuum. This framework for integrated, seamless network navigation from screening through survivorship is represented schematically in Figure 1b (page 32). Our objective is to maintain the DC-PNRP framework for network navigation and to expand integrative navigation services longitudinally at both ends of the spectrum to improve healthcare access for DC residents, in particular the most underserved segment of the population. The goal is to increase the effectiveness of outreach services by including navigators who will direct residents to low-cost screening facilities where those with suspicious findings will become integrated within our already established network navigation. Patients diagnosed with cancer could then be followed through the treatment process and subsequently become integrated within a networked system of navigators trained to assist survivors. ■

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