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## Cancer Patient Navigator Tasks across the Cancer Care Continuum

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### Abstract

Cancer patient navigation (PN) programs have been shown to increase access to and utilization of cancer care for poor and underserved individuals. Despite mounting evidence of its value, cancer patient navigation is not universally understood or provided. We describe five PN programs and the range of tasks their navigators provide across the cancer care continuum (education and outreach, screening, diagnosis and staging, treatment, survivorship, and end-of-life). Tasks are organized by their potential to make cancer services understandable, available, accessible, affordable, appropriate, and accountable. Although navigators perform similar tasks across the five programs, their specific approaches reflect differences in community culture, context, program setting, and funding. Task lists can inform the development of programs, job descriptions, training, and evaluation. They also may be useful in the move to certify navigators and establish mechanisms for reimbursement for navigation services.

### Keywords

Access to health care; case management; certification; health care disparities; indigenous populations; minority health

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Although the United States (U.S.) is seeing reductions in cancer mortality, not all Americans are benefiting equally.<sup>1</sup> Compared with non-Hispanic White Americans, minority and rural-

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dwelling Americans are more likely to under-utilize cancer screening, to be diagnosed with late-stage disease, to fail to complete recommended treatment, and consequently to die from cancer.<sup>2</sup> Disparities in cancer incidence, morbidity, and survival are, in part, due to logistical, structural, and socio-cultural barriers. Patients who live with such barriers also may be unfamiliar or uncomfortable with the U.S. health care system, may not meet provider expectations for knowledge and compliance, or may not resonate with the mainstream culture of care.<sup>3-4</sup>

In line with the *Healthy People 2020* goal to eliminate health disparities (<http://www.healthypeople.gov/>), the National Cancer Institute supported 25 Community Network Programs (CNPs) to engage with diverse groups across the country and in impoverished areas such as the Mississippi Delta and Appalachia, to reduce cancer health disparities (<http://crchd.cancer.gov/cnp/background.html>). Established in 2005, the CNPs use community-based participatory research (CBPR) methods<sup>5</sup> to develop and test approaches to increase use of cancer prevention and control interventions by underserved groups and communities who bear an unequal burden of cancer.

Several CNPs developed and supported cancer patient navigation (PN) programs. A cancer patient navigator is an individual trained to help identify and resolve real and perceived barriers to care, enabling patients to adhere to care recommendations and thus improve their cancer outcomes.<sup>6-8</sup> Cancer PN is rapidly being recognized as an essential service in cancer care, especially for poor and underserved Americans.<sup>9</sup> For example, all 30 medical centers funded under the National Cancer Institute's (NCI's) Community Cancer Center Program (NCCCP) are required to provide cancer PN to reduce cancer health disparities in their communities (<http://ncccp.cancer.gov/index.htm>).

Cancer patient navigators may be professionals (e.g., nurses and social workers), paraprofessionals (e.g., community health workers), or recognized community leaders and peers (including cancer survivors).<sup>10</sup> They may be based in a clinical or community setting. Navigator training usually is provided by the PN program itself, and may vary in length from 16 to 500 hours.<sup>11-15</sup>

Despite these differences among navigators, research suggests that cancer PN is appreciated by patients and that navigated patients are more likely than non-navigated patients to receive timely screening and follow-through with diagnostic tests.<sup>10,16-19</sup> For example, in Robinson-White and colleagues' review of 12 breast-cancer oriented PN programs, findings from nine controlled trials suggest that navigation improved women's adherence to breast cancer screening, follow-up of diagnostic abnormalities, initiation of breast cancer treatment, and quality of life.<sup>19</sup> In another review of controlled trials, Wells and colleagues found that navigation improved adherence to screening by 11-17% and adherence to diagnostic follow-up care by 21-29%.<sup>10</sup>

On the basis of research findings, cancer PN programs have been widely recommended. However, several investigators also have called for more information on the tasks performed by navigators.<sup>10, 19</sup> The literature suggests that a key role of the patient navigator is to coordinate care and/or to encourage patients toward further care.<sup>19</sup> It is also known that the specific roles of the navigator can vary by the navigator's licensure, training, practice setting, and the phase of cancer on which the PN program focuses, e.g., screening, treatment, or survivorship.<sup>10</sup> However, a specific list of navigation tasks is lacking.

The purpose of this study was to identify the key tasks of navigation, based on those performed by navigators affiliated with five CNP programs. To move the field forward, explication of navigator tasks is necessary to inform the development of programs, job descriptions, training, evaluation, certification standards, and reimbursement mechanisms.

## Methods

### Theoretical frameworks

Two frameworks—the continuum of cancer care<sup>20</sup> and the five A's of quality care<sup>21</sup>—guided the identification of key tasks of navigators working with vulnerable populations.

**Cancer care continuum**—The term *cancer care continuum* is used to describe the phases through which a person moves to prevent and control cancer. The continuum is sometimes depicted linearly from prevention to end of life, but phases overlap and repeat. For example, palliative care, provided to relieve symptoms and improve quality of life, has historically been associated with care provided by hospice, targeted to terminal patients with a limited prognosis. Research shows, however, that cancer patients have a better quality of life and longer survival when they receive palliative care concurrently with treatment.<sup>22</sup> Rehabilitation services provided to cancer patients are now considered part of treatment and not often singled out as a phase of the continuum. The term survivorship has been added to the continuum in the past 15 years, and this phase begins at the time of diagnosis and runs through the balance of the cancer patient's life, during which survivors need to return to cancer screening. Our adaptation of the continuum includes six phases: education and outreach, screening, diagnosis and staging, treatment, survivorship, and end of life.

Patient navigation programs focus on one or more phases of the continuum.<sup>10,19,23</sup> Screening navigation programs focus on reaching people in the community, and educating and directing them to screening.<sup>24</sup> Most clinically based PN programs accrue clients at the point of abnormal screening result<sup>16–18</sup> or diagnosis.<sup>25</sup> Some focus on increasing accrual to clinical trials.<sup>26</sup> We used the continuum to organize PN tasks and to describe the phases addressed by navigators affiliated with the five CNPs featured in this study.

**The five A's of quality care**—The second framework underscores that good health care is *accessible, affordable, available, appropriate, and accountable*.<sup>21</sup> The term *understandable* has been added to the framework, making six categories. The objectives of the six categories are shown in Box 1. Within each phase of the continuum, navigators take steps to ensure that cancer information is understandable to their clients so clients can participate fully and actively in care. Navigators help clients learn which cancer services are available, and also link them to programs that provide transportation, housing, nutritional supplements, stipends, medications, and so forth. Navigators make care more accessible by helping patients make and keep appointments, find transportation, complete forms, and understand instructions (providing or organizing language translation and interpretation if needed). Navigators can keep care affordable by helping clients obtain insurance coverage, tap community funding sources, and sign-up for free or low-cost services and products. Navigators link clients to diagnostically and culturally appropriate services, develop linguistically appropriate materials where none exist, and educate providers about cultural values and preferences of their clients. Finally, Navigators keep services accountable by participating in evaluation and quality improvement activities and advocating for service expansion and reimbursement.

### Sample

We polled the 25 Community Network Programs (CNPs) programs to determine which were offering or affiliated with cancer PN programs. We excluded CNPs that had offered navigation in the past (e.g., in the context of a pilot study). Five CNPs qualified for inclusion and assigned representatives to provide data on the cancer PN programs with which they were affiliated.

## Measures

Community Network Program representatives followed an interview guide to document the phases of the cancer care continuum addressed, navigator qualifications, training protocols, and funding sources. To document tasks, a grid-like worksheet was created based on two frameworks, with the quality of care categories along the x-axis and the phases of the cancer care continuum along the y-axis. Community Network Program representatives worked with navigators or their supervisors to list the tasks performed relevant to each cell. For example, for the cancer screening phase of the continuum, we documented what the program's navigators did to ensure that screening was understandable, available, accessible, affordable, appropriate, and accountable.

## Analysis

Two authors (BFS, MKS) merged tasks across programs, producing a grid that reflected the range of tasks provided in each cell. They were joined by another author (KLB) to further refine the grid and to create separate tables for each of the six phases of the continuum. These tables (available upon request) were shared with all authors, who provided further refinements, which were agreed upon by all. For purposes of publication, the six tables were condensed into a single table. Finally, CNP representatives asked navigators for specific examples about how they performed the tasks for patients in a specific phase of the continuum. These cases illustrate how navigators perform tasks within the contexts of the underserved communities within which they work.

## Results

Two common characteristics of navigators affiliated with five CNPs were: 1) they were hired from the underserved communities served by the CNP with the express purpose of increasing access to care; and 2) their jobs did not require clinical degrees. These five PN programs serve American Indians, Alaska Natives, Native Hawaiians, Pacific Islanders, Latinos, African Americans, immigrant Asian Americans, and underserved, low-income non-Hispanic White Americans. First presented is a brief overview of five CNP-affiliated navigation programs (Box 2). Then presented are the navigator tasks or functions for each phase of the cancer care continuum, illustrated by case examples (using pseudonyms) of how navigation programs differ to best fit their clientele, community, and cultural context.

### Five CNP-affiliated navigation programs

**Native American Cancer Research (NACR)**—The NACR navigator program evolved from the Native American Women's Wellness through Awareness (NAWWA) program supported by the Robert Wood Johnson Foundation in 1994.<sup>12–13</sup> Currently, NACR employs three grant-funded Native American navigators in Denver (called Native Sisters), and works with 12 subcontracted Native Patient Advocates/Navigators in other states. About half of these individuals have at least a baccalaureate degree. These 15 NACR-trained navigators each have completed 125 hours of training, followed by refresher and supplemental trainings. From 1996 through 2010, the Native Sisters and Native Patient Advocates/Navigators provided outreach to innumerable Native communities and helped more than 800 Native women and men access screening, diagnostic services, treatment, survivorship, and end-of-life care. Since 2005, this program has been affiliated with Spirit of Eagles, the CNP based at the Mayo Clinic in Rochester, Minnesota that addresses Native American and Alaska Native cancer disparities across several U.S. states.

**Hands of Hope**—In 2008, the Carolina Community Network in North Carolina and the Lineberger Comprehensive Cancer Center at the University of North Carolina Chapel Hill (UNC) developed the Hands of Hope program to provide navigation in rural underserved

communities of North Carolina. Patient navigation services are provided by a Cancer Support Coordinator and two oncology nurse navigators, assisted by a cadre of volunteer navigators. The UNC Volunteer Coordinator presents a short orientation about navigation to potential navigators identified through community groups and churches. Interested individuals complete two free, online, self-paced tutorials on PN offered through the Colorado Patient Navigation Training website (<http://patientnavigatortraining.org/website/faq/htm>). Following this, volunteer navigators receive experiential and continuing didactic training. In 2009 and 2010, 78 volunteer navigators (about 30% of whom are cancer survivors) completed training. Volunteer navigators work with the paid nurse navigators to provide community education sessions and promote cancer screening. Annually, about 50 individuals with cancer are navigated through treatment by the nurse navigators, and volunteer navigators may assist them.

**PATH for Women**—Sponsored by the Orange County Asian Pacific Islander Community Alliance (OCAPICA), the PATH for Women PN program grew from a CDC-funded assessment of cancer care needs among Asian and Pacific Islander (API) minorities.<sup>14–15</sup> Bilingual-bicultural navigators serve Chamorro, Marshallese, Native Hawaiian, Samoan, Tongan, Cambodian, Hmong, Lao, Thai, and Vietnamese Americans living in the greater Southern California area. Navigation training is provided to interested individuals from API communities, including outreach workers, cancer survivors, and family members. About 40 navigators have been trained since 2000. Two navigators currently employed by OCAPICA and eight employed by other agencies have each received about 500 hours of training relevant to navigation and medical interpretation. Although few of these navigators work full-time, between 2001 and 2009 they provided direct outreach to 141,293 community members and helped 4,920 women access screening, diagnostic, treatment, and survivorship services. Funding also is received from Susan G. Komen for the Cure®, and PATH for Women is affiliated with the CNP Weaving an Island Network for Cancer Awareness, Research, and Training.

**Redes En Acción National Patient Navigator Intervention Study**—The CNP *Redes En Acción* National Latino Cancer Research Network received NCI research funding in 2008 to test the efficacy of PN. Headquartered at the Institute for Health Promotion Research at the University of Texas Health Science Center at San Antonio, *Redes En Acción* supports navigators at six sites—San Antonio, South Texas, New York, San Francisco, San Diego, and Miami. These navigators are Hispanic, bilingual in Spanish, and have at least a bachelor's degree; one has a master's degree in public health (MPH) and another is a medical doctor (MD). Navigators completed eight hours of training in navigation and 18 hours of training on the research database and receive continued training through monthly teleconferences. Since its inception, *Redes En Acción* navigators have helped 300+ individuals with cancer screening, diagnosis, and treatment.

**Kukui Ahi**—Moloka'i General Hospital is the sponsor of *Kukui Ahi*, a Hawaiian phrase meaning to *show the way*. This PN program is affiliated with the 'Imi Hale Native Hawaiian Cancer Network, a CNP based at Papa Ola Lokahi, a community agency in Honolulu, Hawai'i. 'Imi Hale helped write grant proposals to support PN on the island of Moloka'i because 60% of the residents of this small rural island are Native Hawaiian and experience multiple barriers to care. Initially funded in 2006 through the Center for Medicare and Medicaid Services (CMS, [http://www.cms.hhs.gov/demoprojectsevalrpts/downloads/CPTD\\_FactSheet.pdf](http://www.cms.hhs.gov/demoprojectsevalrpts/downloads/CPTD_FactSheet.pdf)), *Kukui Ahi* now is supported by Health Resources and Services Administration, NCI (through 'Imi Hale), and The Queen's Medical Center in Honolulu. *Kukui Ahi's* Native Hawaiian and Filipino navigators have at least high school diplomas, have completed 'Imi Hale's 48-hour



navigator training<sup>11</sup> and participate in continuing education. Between 2006 and 2010, navigators assisted 154 Medicare-eligible Moloka‘i residents to cancer screening and 88 cancer patients (regardless of age and insurance status) with diagnosis, treatment, survivorship, and end-of-life care.

### Navigator tasks across the cancer care continuum

Presented in Box 3 are the key tasks performed by navigators working with underserved groups. Tasks are organized by stage along the continuum and by their intent to make sure that cancer services are understandable, available, accessible, affordable, appropriate, and accountable to these groups. Note that navigators may perform similar tasks (e.g., offering education) in several or all phases of the continuum. However, the specifics of the task vary. For example, education in phase 1 (outreach and education) is provided to help reduce fear and stigma of cancer and communicate the value of early detection, whereas education in phase 6 (end-of-life) is provided to help clients understand prognosis, advance directives, palliative care, and hospice. Navigators also tailor their delivery to address community context and maximize available resources.

**Phase 1: Education and outreach**—In this phase of the continuum, navigators use their knowledge of the community to increase awareness of the value of early detection. For example, *Kukui Ahi* serves many older Filipinos. Knowing that there is no word for *cancer* in Tagalog or Ilokano (the two Filipino languages spoken by *Kukui Ahi*'s Filipino clients) the navigator developed this analogy: “It’s like when you plant *talong* (eggplant), sometimes weeds start to grow. The plant is your good cells, and the cancer is the weeds. You have to get rid of the weeds, or the good cells will die. When you go for screening, the doctor is looking for cancer while it is small. Just like in farming, you want to get rid of the small weeds right away...you don’t wait for the weeds to take over the *talong*.”

The PATH for Women navigators often develop in-language materials with culturally salient images to assist in their outreach efforts. For example, the Lao navigators produced a calendar with images from Laos, educational messages, and reminders for cancer screening. This gift helps to build trust and facilitates conversation about general health and, eventually, cancer. The Lao navigators provide education and meet clients at Buddhist temples and Lao cultural celebrations, knowing that members of this community do not seek information at clinics.

**Phase 2: Cancer screening**—In this phase of the continuum, navigators use different approaches to increase screening among underserved individuals. The NACR program found that many Native American women did not have mammograms because of difficulties accessing medical centers. A Native American woman recalls, “I told them [Native navigators] it was hard for me to go to the medical center, and they invited me to have my mammogram at NACR’s office in the mobile mammogram van that parks there several times a year. I am used to going to NACR, so this made it so easy to get screened, and the ladies [navigators] made me feel so comfortable.”

*Kukui Ahi* navigators report major changes in receptivity to screening. In Hawaiian culture, there is a belief that saying the word *cancer* may bring it on and that cancer screening procedures are painful.<sup>27</sup> Hence, elders initially were reluctant to discuss cancer or participate in screening. This was overcome by continuous outreach and education and finding those elders willing to “take a leap of faith to get screened.” Of course, the majority of those screened did not have or get cancer. Elders then communicated to others that the procedures were “not so bad.” Men were especially surprised at the ease of the PSA test.

**Stage 3: Diagnosis and staging**—Because individuals with suspicious screening results can be lost to follow-up, navigators play major roles in helping clients get their cancers diagnosed and staged. For example, “Khun-Oi,” a Thai immigrant, had met a Thai navigator at an outreach event sponsored by PATH for Women. Khun-Oi contacted her when she found a lump in her breast. The navigator arranged Khun-Oi’s appointment with the state’s federally sponsored breast cancer screening program, accompanied Khun-Oi to the appointment, and helped her complete forms and eligibility paperwork to qualify for no-cost services. After the clinical breast exam, the navigator drove Khun-Oi to the imaging center for the screening mammogram. When Khun-Oi got a report of “abnormal result,” she contacted the Thai navigator to explain the findings. Over the next five weeks, the navigator accompanied Khun-Oi for the diagnostic mammogram, breast ultrasound, and fine needle aspiration, and was on hand to explain the definitive diagnosis—stage II breast cancer. Because the Thai navigator knew to arrange the initial screening mammogram through the state and federally sponsored breast cancer screening program, Khun-Oi’s cancer treatment was covered.

While helping an uninsured man with brain cancer, Hands of Hope navigators discovered that his wife was forgoing care for her recently diagnosed breast cancer because of the financial strain on the family. A network of volunteer PNs assisted them with financial assistance applications, transportation to appointments, and support with daily needs.

**Phase 4: Cancer treatment**—In this phase of the continuum, navigators perform tasks that reduce the elapsed time between diagnosis and treatment, and help individuals complete treatment. For example, a *Redes En Acción* navigator contacted “Maria” after she had missed her appointment to start treatment. In their discussions, the navigator learned that Maria had misinterpreted the Carelink program (an indigent medical program in San Antonio). Having reached her maximum liability, she thought she could not receive treatment. The navigator educated her about the hospital’s responsibility to cover additional medical expenses and addressed barriers related to lack of transportation and childcare, non fluency in English, need for support and accompaniment during treatment, misunderstandings about the informed consent process, and the potential need for blood transfusions. Without steady support of the navigator, Maria would not have initiated or completed treatment.

*Kukui Ahi* helped Lani from Moloka‘i, who had moved her family to Honolulu for a job that provided her health insurance. She had been diagnosed with gall bladder cancer, and needed chemotherapy and radiation. Her husband became very angry about her condition and told her to leave their house. *Kukui Ahi* navigators helped find Lani and her children another place in Honolulu to live so she could keep her job and be close to treatment facilities. They also helped her apply for financial help, get nutritional supplements, and provided a ready source of psychological support. Navigators also provided emotional and logistical support to Lani’s mother, who helped watch the children while Lani completed treatment.

Navigators with NACR illustrate how they make the cancer care system more accountable to Native American women. “When we apply for Medicaid or Medicare, about 30% of the time the patient’s paperwork is rejected, because many times the worker mistakenly believes that Indian Health Service (IHS) will cover all care. However, IHS is not a health insurance program, and many Native Americans do not live near an IHS hospital. Navigators must advocate on behalf of the client to have paperwork reinstated within the CMS. Through efforts like offering staff training on Native American cultural awareness, NACR has built relationships with funders and program managers who facilitate communication about and resolution of client-related problems.

**Phase 5: Survivorship**—Cancer is stigmatized and considered a death sentence in many underserved communities. Navigators must help individuals adjust to living with cancer and return to a regular cancer screening routine post treatment. For example, the PATH for Women program links its Samoan clients to Samoan-language cancer support groups. Members are encouraged to share their stories, and their survivorship demonstrates to others that *kanesa* (Samoan for *cancer*) is not necessarily fatal. The group also serves as a safe place for families and survivors to discuss cancer-related challenges, including fear of recurrence. Some members visit individuals undergoing treatment to give them strength, and others become role models in the community, encouraging peers to participate in cancer screening.

The Native Sisters of NACR knew “Twila” since 2006, when she started having her mammograms in the Mobile Mammography Van. She was diagnosed with breast cancer in 2008 and, soon after, her husband suffered a fatal heart attack. Besides accompanying her to appointments and advocating on her behalf with Medicaid, the Native Sisters encouraged Twila to join their Survival Support Group. As a cancer survivor, Twila now is back to her routine of regular mammograms and checkups. She volunteers for NACR events and functions, speaks publically about cancer survivor issues, and refers other Native Americans to NACR.

**Phase 6. End-of-life**—Although rates of survival are increasing, some individuals will die with cancer, and navigators can help in this phase of the continuum. One of the *Kukui Ahi* navigators noted, “When a client is terminal, we work hard to take a neutral position relative to cancer treatment. We provide information and allow them to make their own decisions about continuing chemotherapy and other treatments. If a client starts saying he is ‘tired of treatment and pain’ and ‘it’s time to return to God,’ we discuss what the client and family want of the future, and provide information about advance directives, palliative care, and hospice. When there are questions we cannot answer, we link the client to the oncologist or social worker at our hospital. We also ask if they would like us to arrange a visit from their priest or pastor, and we respect their decision.”

“Paul,” a Native American client with terminal lung cancer, hesitated to share his diagnosis with his children because he didn’t want them to worry or fear for him. After discussions with the NACR navigators, Paul and his wife decided to tell the rest of the family to allow them time to deal with the diagnosis together. Navigators helped the couple plan the moment of truth-telling. They also provided information about the condition, treatments, and what to expect. They helped the couple talk through their fears about death. The family rallied around Paul and became his greatest source of strength. When the final weeks came, navigators helped arrange home hospice care, and Paul was able to participate in traditional and contemporary prayer ceremonies that were held for him.

## Discussion

In this paper, we articulated the variety of tasks that cancer patient navigators perform across the cancer care continuum—from education/outreach through end-of-life care—recognizing that different programs sponsor navigators who address various phases of the continuum. The case examples illustrated how, in performing these tasks, navigators make sure their clients find cancer care understandable (by providing education to improve knowledge, attitudes, and practices regarding cancer), available (by knowing about services and linking clients to them), accessible (by removing structural and cultural barriers to services), affordable (by enrolling clients in insurance, free, and low-cost programs for which they are eligible), appropriate (by offering culturally competent services and educating mainstream



providers about the needs and cultures of their clients), and accountable (by participating in efforts to improve and expand services).

The use of two conceptual frameworks—the *cancer care continuum* and the *5 As*—helped in the articulation of these tasks.<sup>20, 21</sup> As shown in Box 3, similar tasks (e.g., identify free and low-cost resources and explain things in client’s language) are performed across the continuum. Our detailed tasks lists (available on request) include more specification on tasks in each phase of the continuum. These tasks-by-phase lists may be very helpful to community groups and clinical settings that want to develop PN programs to increase access to cancer care among underserved groups. Lists can be used to help organizations sort out which phases of the continuum they want navigators to address, to craft job descriptions, and to build training programs. They can be used to describe the navigator role to potential hires and guide the job interview process. For PN programs that use professional health care providers as navigators, the lists could be expanded to include tasks that these professionals could perform based on their credentials, for example medication management in the case of registered nurses and psychosocial counseling in the case of licensed social workers. Finally, lists may be useful, with further refinement, in efforts to certify navigators, a necessary step on the path toward federal reimbursement for navigator services.<sup>10</sup>

To assure entrée into underserved communities, the featured PN programs recruited respected individuals from the underserved groups they served with the express purpose of reducing cancer health disparities experienced by these groups. Although not required by the featured PN programs, several navigators employed by these programs had clinical or advanced degrees in addition to meeting the other selection criteria. As the stories in this article suggest, a professional degree is not essential to helping individuals access cancer care. In recruiting individuals to navigator positions, however, some personal qualities are important. For example, potential navigators must have the capacity to learn about cancer, track cancer services, communicate with professionals, and know when and where to refer clients for help. They must be personable and committed to improving the lives of others, and able to maintain patient confidentiality. They must be willing and able to educate mainstream providers about the cultural strengths and structural barriers of their communities and advocate for expanded services. At the same time, they must be cultural brokers and interpreters for their clients and not make decisions for them.

Once hired, navigators must be oriented and trained. The five featured PN programs differed in the number of training hours and training formats. However, all training programs covered a number of basic competencies, including the role of the navigator, confidentiality, listening and communication, identifying barriers, and locating resources to help overcome barriers. Training programs also must provide basic information on cancer and cancer prevention, and more detailed information on screening tests and common treatments for the cancer(s) on which the PN program focuses. *Kukui Ahi*, NACR, and PATH for Women training programs also train navigators on survivorship and end-of-life care and utilize role playing and peer education to help navigators hone skills in assessment, care planning, and negotiation. NACR and PATH for Women also provided training in advocacy, program planning and evaluation, CBPR, developing health education materials, and establishing and leading cancer support groups. PATH for Women additionally encourages navigators to complete certified courses in medical interpretation. In general, programs with navigators that address more phases of the continuum require more hours of training, and longer trainings include tours of cancer care facilities and opportunities to build relationships with practitioners, in addition to lectures and role play. All five programs realize that navigators require continuing education. Related to careful recruitment and training is the need to retain navigators. Although navigators may be seen as relatively inexpensive extenders of cancer

care, salaries must be sufficient to recognize their expertise and value, minimize turnover, and maximize community trust.

Another difference among PN programs is their base of operations, and this base may have implications for the tasks navigators can perform. Activities related to record keeping, for example, vary widely. The PATH for Women program is sponsored by a community organization, and they help their clients maintain their own cancer records and reports. NACR’s Native Sisters also are situated in a community-based organization, but work with clinics and hospitals to meet their HIPAA-related requirements and develop Memoranda of Understanding for data sharing. This allows them to move freely throughout the hospital and interact with staff on their clients’ behalf, but not to directly access hospital medical records. Rather, navigators help clients maintain their own records and then summarize records on an online protected database. The *Kukui Ahi* navigators are based in Moloka’i General Hospital, so have direct access to client medical records and the professional care team.

Cancer care must be accountable, and our lists include tasks related to evaluation and quality assurance. To capture outcomes, each featured PN program uses a different database, some dictated by their funder and others homegrown. Our ability to secure reimbursement for PN services will depend on credible process and outcome data. Although a number of controlled trials suggest PN efficacy, local funders and insurers often desire evidence that programs are effective locally. Cancer PN programs should collect data to track key PN outcomes—increasing adherence to screening recommendations, reducing the proportion of late-stage diagnoses and increasing the timeliness and completeness of treatment. It also would be interesting to see which task or set of tasks link to these key outcomes.

In conclusion, this article lists and illustrates tasks that navigators perform across the cancer care continuum. We believe that recruiting, training, and retaining individuals from underserved communities to carry out these tasks can help reduce the cancer health disparities experienced by poor and underserved individuals in the U.S. We also believe that these task lists provide essential information for administrators developing or expanding cancer PN programs and for the certification and reimbursement of this important service.

**Box 1**  
Navigator Quality of Care Strategies and Objectives

Strategy	Objective for specific community of focus
<ul style="list-style-type: none"> <li>• Understandable</li> <li>• Available</li> <li>• Accessible</li> <li>• Affordable</li> <li>• Appropriate</li> <li>• Accountable</li> </ul>	<ul style="list-style-type: none"> <li>• To provide education to improve knowledge, attitudes, and practices regarding cancer</li> <li>• To map out the location of and identify contact individuals for cancer services and to advocate for services to fill service gaps</li> <li>• To remove structural and cultural barriers to services, assuring that what is available can be accessed</li> <li>• To assure that individuals are enrolled in insurance, free, and low-cost programs for which they are eligible so that cost is not a barrier</li> <li>• To establish culturally competent services and staff at facilities and programs utilized by community members</li> <li>• To assure the sustainability, quality, cultural appropriateness, and responsiveness of the cancer services to and for the population(s) of focus</li> </ul>

**Box 2**  
Overview of required qualifications of navigators, training, funding, and evaluation of five CNP navigation programs

	Hired Navigators and education	Training for navigators	Venue	Phases of Continuum <sup>a</sup>	Funding
Moloka'i General Hospital	Three individuals from Molokai community with at least HS diploma.	48 hr training from 'Imi Hale, plus regular CE	Paid navigators are hospital based	All 6 phases	CMS, HRSA, Queen's Medical Center
OCAPICA	5 of 10 paid bilingual community health workers with at least HS diploma	400 hrs including medical interpreter training and ongoing CE	Paid navigators are community based	Phases 1-5	CDC, Susan G. Komen, Los Angeles County Affiliate
NACR	7 of 14 paid navigators have BA/BS or higher	125+ hours plus regular CE for navigators on staff	Paid navigators are community based	All 6 phases	NCI, CDC, State of Colorado
Redes	Hispanic, bilingual individuals with BA/BS from target communities trained post-hire.	26 hours plus regular CE	Paid navigators work in clinic, hospital and community settings	Phases 1-5	NCI
Hands of Hope, UNC	2 RN navigators hired to provide navigation and to train and coordinate the work of volunteer navigators.	4 hours initial training, 4 hours orientation, and ongoing CE	Paid RN navigators and volunteer navigators are community based	Volunteer navigators focus on Phases 1 and 2; RN navigators on Phases 2-4	Univ of North Carolina and community fund raisers.

<sup>a</sup>Phases include: 1=education/outreach; 2=screening; 3=diagnosis/staging; 4=treatment; 5=survivorship; 6=end-of-life.

**Box 3**  
Tasks of Cancer Patient Navigators over the Cancer Care Continuum<sup>a</sup>

TASKS	PHASES					
	1	2	3	4	5	6
<b>A-1 Understandable</b>						
1. Offer education.	√	√	√	√	√	√
2. Help clients and families find additional information from websites & agencies.	√	√	√	√	√	√
3. Maintain library of appropriate materials.	√	√	√	√	√	√

<u>TASKS</u>	<u>PHASES</u>					
	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>
4. Work w/ providers to increase their understanding of community's history, culture, and needs, as well as the cultural appropriateness of their approaches and materials	√	√	√	√	√	√
<u>A-2 Available</u>						
1. Maintain directory of services and service logistics, procedures, & amenities.	√	√	√	√	√	√
2. Maintain a bank of application & eligibility forms for programs.		√	√	√	√	√
3. Encourage providers to expand programs and ability to serve community of interest.	√	√	√	√	√	√
4. Develop relationships with providers, eligibility workers, & programs offering free & low-cost services.	√	√	√	√	√	√
	√	√	√	√	√	√
5. Develop new services to meet needs, e.g., ethnic-specific support groups.			√	√	√	√
6. Advocate for additional services & reimbursement for services.	√	√	√	√	√	√
<u>A-3 Accessible</u>						
1. Offer education through cultural gathering sites and events.	√	√	√	√	√	√
2. Utilize ethnic minority media & ethnic venues to promote messages & PN services.	√	√	√	√	√	√
3. Build bridges to diverse service organizations.	√	√	√	√	√	√
4. Help clients make appointments, & remind them of appointments.		√	√	√	√	√
5. Assist clients with intake & other forms.		√	√	√	√	√
6. Arrange transportation & accompany client if appropriate		√	√	√	√	√
7. Assist families in renegotiating roles so that client can get screening & treatment.		√	√	√	√	√
8. Address other structural, cultural, & emotional barriers to care.		√	√	√	√	√
<u>A-4 Affordable</u>						
1. Offer free or low-cost education & PN services	√	√	√	√	√	√
2. Identify free or low-cost resources.	√	√	√	√	√	√
3. Help client w/ paperwork for insurers & free & low-cost programs.		√	√	√	√	√
4. Work with others to secure grants to support PN & cancer care services.		√	√	√	√	√
5. Coordinate w/ other agencies & providers to co-sponsor events.	√	√			√	
6. Collaborate w/ local and national companies for appropriate incentives & services.	√	√	√	√	√	√
<u>A-5 Appropriate</u>						
1. Explain things in client language.	√	√	√	√	√	√
2. Provide or link to medical interpretation.		√	√	√	√	√
3. Help clients maintain modesty & respect during screening, tests, & care.		√	√	√	√	√

<u>TASKS</u>	<u>PHASES</u>					
	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>
4. Consider clients' strengths in delivering services & helping them marshal support.		√	√	√	√	√
5. Encourage providers to hire diverse staff.		√	√	√	√	√
6. Clarify preferences for cultural practices; if appropriate, contact cultural or spiritual leaders to support client and family with traditional practices.			√	√	√	√
<u>A-6 Accountable</u>						
1. Understand the available culture of care	√	√	√	√	√	√
2. Help clients secure & maintain records.		√	√	√	√	√
3. Help client document treatment choices & care preferences.				√	√	√
4. Document PN services provided, as well as barriers & successes.	√	√	√	√	√	√
5. Participate in quality assurance & evaluation of PN services.	√	√	√	√	√	√
6. Establish agency and self as trustworthy, credible resource.	√	√	√	√	√	√
7. Provide reports to community on PN & other cancer care services.	√	√	√	√	√	√

<sup>a</sup> 1=education/outreach, 2=screening; 3=diagnosis/staging; 4=treatment; 5=survivorship; 6=end-of-life.

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