

PUT AN END TO THE  
**EPIDEMIC**

**ORGANIZATIONAL EFFECTIVENESS SERIES:  
BUILDING HEALTHY ORGANIZATIONS**

**HIV NAVIGATION SERVICES  
A GUIDE TO PEER &  
PATIENT NAVIGATION  
PROGRAMS**

Tools and Resources for Building Healthy Organizations



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# HIV Navigation Services Toolkit

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# CHAPTER 1: INTRODUCTION

## Objectives:

- To explain the purpose of the Patient Navigation Guide
- To describe Centers for Disease Control and Prevention (CDC) expectations for patient navigation as a component of high-impact prevention programs for community-based organizations funded through Funding Opportunity Announcement (FOA) PS15-1502
- To describe the scope and contents of the guide
- To help users of the guide easily find information they need

## Purpose of the Guide

The Patient Navigation Guide provides information and tools designed to help grantees funded under RFP PS15-1502, Comprehensive High-Impact HIV Prevention and Care Projects for Community-Based Organizations (CBOs) meet the FOA's new requirement that their programs include a Navigation and Prevention and Essential Community Support Services component. Navigation services are required for prevention with HIV-positive and high-risk HIV-negative individuals; the guide focuses on navigation models for HIV-positive individuals. Target populations include both newly diagnosed HIV-positive individuals and previously identified people who have either fallen out of care or never entered care.

**The FOA requires** that Comprehensive HIV Prevention with HIV-Positive Individuals include a navigation program:

“Applicant organizations are required to develop or enhance systems for assisting clients with navigating services (obtaining necessary information, support, and skills to access complex medical systems) for HIV-positive persons at all stages of care, treatment, prevention, and essential support services. The Navigation and Prevention and Essential Support Services component must include, but is not limited to the following:

1. Training navigators (e.g., community health workers, peer advocates, outreach workers) to provide or refer HIV-positive persons to prevention and essential support services.
2. Providing and navigating services (e.g., accompanying persons to medical appointments, providing or referring to prevention and essential support services) that reduce and/or eliminate barriers to medical care and services that address acceptance, responsibility, and behavior change.”<sup>1</sup>

**The guide will help grantees** prepare for navigator training and development, and for implementing programs that “help facilitate access to (linkage and re-engagement) and retention in medical care and refer or provide prevention and essential support services,” as

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<sup>1</sup> See FOA PS15-1502, page 23.

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specified in the FOA. Newly diagnosed individuals are to be linked to care within 90 days after diagnosis.

**The guide uses the terms *navigator* and *community navigator*.** *Navigator* is the primary term specified in the FOA. In addition, the guide sometimes uses *community navigator* to emphasize that the focus is on identifying and training lay or paraprofessional navigators – since the FOA specifies that the navigators are to be individuals such as *community health workers (CHWs)*, *peer advocates*, and *outreach workers*, rather than professionals such as registered nurses (RNs) or social workers.

**Targeted users of the guide** are senior and mid-level executives of grantee CBOs responsible for meeting the FOA requirement for developing and implementing navigator programs.

## Scope of the Guide

The guide provides information, documented models, suggested strategies and tasks, and tools and resources to use in planning and implementing patient navigation (PN) programs that facilitate successful linkage to and retention “at all stages of care, treatment, prevention, and essential support services.”<sup>2</sup> It offers guidance and resources for each major task in PN program development. The guide identifies sources for training courses and curriculum modules but does not provide training curricula. It also provides references and explanatory footnotes with links to documents that can help you design or enhance your PN program.

More specifically, the remaining chapters of the guide include the following:

- **Chapter 2, Patient Navigation: Past, Present, and Future:** History and development of patient navigation, typical definitions of patient navigation and typical roles of navigators, and an overview of the current status of PN, including its use in varied health care settings and its focus on various diseases.
- **Chapter 3, Benefits of Patient Navigators: For Patients, CBOs, and the Health Care System:** A review of documented results and benefits of PN, including how it affects patients, CBOs, clinical service providers, and the health care system.
- **Chapter 4, Lessons from Patient Navigator Programs:** Lessons learned from five successful and diverse PN programs profiled in Chapter 5 and from other PN programs, including factors that contribute to PN program effectiveness, common program challenges, pitfalls and problems and ways to avoid or minimize them.
- **Chapter 5, Patient Navigation Program Profiles:** Detailed charts profiling five diverse patient navigation programs, including three that are HIV-focused.
- **Chapter 6, Incorporating PN Programs:** Factors to consider and suggested strategies to use in PN program development and implementation. Includes guidance and tools for designing a PN program, getting buy-in from key components of the organization, addressing legal and regulatory issues, meeting Health Insurance Portability and Accountability Act (HIPAA)
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<sup>2</sup> As stated in FOA PL15-1502.

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and confidentiality requirements, hiring and managing navigators from the community, and addressing other program and organizational needs.

- **Chapter 7, Conclusion:** Summary of guide lessons and key take-aways, including suggested action steps for getting started with PN program design.

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## CHAPTER 2: PATIENT NAVIGATION: PAST, PRESENT, AND FUTURE

### Objectives:

- To define and describe patient navigation
- To describe the roles of a patient navigator
- To describe patient navigation programs focusing on different diseases and populations
- To describe the history of patient navigation in the United States
- To describe the current status of patient navigation

### Definitions and Descriptions of Patient Navigation

Patient navigation has no single accepted definition or scope of services, but is widely understood as a component of health care delivery that provides individualized assistance to patients to help them obtain timely medical care and support services and to address barriers to care. It often focuses on either newly diagnosed individuals with a life-threatening disease or individuals with a serious chronic illness who have not been receiving regular medical care or have been unsuccessful in managing their illness. PN can also be used to help prevent diseases such as HIV or diabetes, most often through targeting individuals at high risk and helping to provide or arrange health education and behavior change interventions.

Following are four descriptions of PN that demonstrate both the commonalities and differences across PN programs. All emphasize the direct link to medical care, but then add a variety of related issues: removing barriers and changing attitudes and behaviors, providing services from testing through the end of life, and ensuring culturally competent services. They come from the CDC's Dr. Harold P. Freeman, generally viewed as the father of patient navigation, and from a cancer care organization.

- **From the CDC website:** "HIV navigation is a process of service delivery to help a person obtain timely, essential and appropriate HIV-related medical and social services to optimize his or her health and prevent HIV transmission and acquisition. Navigation includes linking persons to health care systems, assisting with health insurance and transportation, identifying and reducing barriers to care, and tailoring health education to the client to influence his or her health-related attitudes and behaviors."<sup>3</sup>
- **From The Harold P. Freeman Patient Navigation Institute:** "*Patient navigation is a patient-centric healthcare service delivery model. It is a patient-centric concept that concentrates on the movement of patients along the continuum of medical care. It is a comprehensive term, to include all steps through this broad and diverse continuum,*

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<sup>3</sup> From the CDC website, Effective Interventions: HIV Prevention That Works, HIV Navigation Services. Provides several PN resources. See <https://effectiveinterventions.cdc.gov/en/HighImpactPrevention/BiomedicalInterventions/HIVNavigationServices.aspx>

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beginning in the community and continuing on through testing, diagnosis, and survivorship to the end of life.”<sup>4</sup>

- From Patient Navigation in Cancer Care: “Patient navigation is a process by which an individual—a patient navigator—guides patients with a suspicious finding (e.g., test shows they may have cancer) through and around barriers in the complex cancer care system to help ensure timely diagnosis and treatment....

“Patient navigation helps ensure that patients receive culturally competent care that is also:

- Confidential
- Respectful
- Compassionate
- Mindful of the patient's safety”<sup>5</sup>

Increasingly, the essential focus of navigation is described as *helping patients overcome barriers to timely and appropriate care*. This can require a range of activities because each patient faces somewhat different barriers.

**Types of Navigators:** Navigators can be “lay people” from the community, including peers (individuals who have the same disease and/or life experiences similar to those of the people they are assisting), trained and sometimes certified CHWs or *promotores de salud* (health promoters), outreach workers, individuals with certificates or Associate degrees in fields related to health care, degreed social workers, or medical professionals such as RNs, Nurse Practitioners, Physician Assistants, and physicians. Some experts believe that navigation tasks sometimes need to be split between community workers and medical professionals, with tasks such as providing information on medication and side effects left to the clinical professionals, and roles such as helping with making and keeping appointments and resolving barriers to care assigned to the community workers. The CDC FOA notes that navigators can be “peers, volunteers, and staff members of clinics, health departments, and community-based organizations. Patient navigators may be lay persons, paraprofessionals, or medical professionals (e.g., RNs, Nurse Practitioners).”<sup>6</sup>

Most current PN programs, especially those that are clinic or CBO based, appear to use a CHW or similar model. The navigators are paraprofessionals, individuals who have training to prepare them for their navigation roles and responsibilities but not necessarily formal health care training or a health care-related post-secondary degree. The CDC FOA describes navigators hired by its grantees as likely to be “community health workers, peer advocates, or outreach workers.”<sup>7</sup>

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<sup>4</sup> The Harold P. Freeman Patient Navigation Institute, a nonprofit organization site that provides considerable useful historical and descriptive information about patient navigation. See <http://www.hpfreemanpni.org/faq/>

<sup>5</sup> Patient Navigation in Cancer Care, a website developed by Pfizer, Inc. Good background information from a cancer care perspective. See <http://www.patientnavigation.com/what-is-patient-navigation>

<sup>6</sup> See FOA PS15-2012, page 73.

<sup>7</sup> See FOA PS15-1502, page 23.

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**Settings:** PN programs can be based in a variety of health care and support service organizations, among them community-based clinics, CBOs providing social services, hospitals and hospital clinics, other public health nonprofits, public health institutes or associations of clinical providers, and even private physician groups. HIV-focused PN programs may use a model in which a single organization is responsible for hiring and training; service providers agencies may then hire the trained navigators, or they can be employed centrally and outstationed in federally qualified health centers (FQHCs), other community clinics, hospitals, health departments, and non-clinical CBOs, including groups providing medical case management. Breast cancer-focused PN programs are operated out of FQHCs and other community clinics, hospitals, and CBOs that exist specifically to help women obtain mammograms and needed follow-up services. PN programs typically have close relationships with medical providers, since their primary purpose is to help patients obtain needed services from the health care system.

**Scope and Duration of Navigation:** The scope of PN programs varies considerably, based on disease-specific needs and differing views of the best use of navigators. Some PN programs are relatively short-term, focusing on helping clients enter and become well connected to treatment. Others involve intensive services for a limited period to people with chronic illnesses, to link them to care and prepare them for disease self-management, then less intensive follow up—but services remain available if the patient faces new or renewed obstacles and needs additional support. Total duration typically ranges from three months to two years. However, some, including many cancer-focused PN programs, begin with community outreach and continue through treatment to follow up, survivorship, and end-of-life services.

**Navigator Roles:** CDC expects the patient navigation programs developed for its grants to “help facilitate access to (linkage and re-engagement) and retention in medical care and refer or provide prevention and essential support services.”<sup>8</sup> These roles specifically involve helping patients to enter and remain in appropriate medical care and obtain needed support services. One PN organization summarizes navigator roles as helping to “coordinate patient care, connect patients with resources, and help patients understand the healthcare system.”<sup>9</sup> Often navigators, particularly those employed by hospitals or clinics, are considered members of the clinical team. Their roles are closely linked to medical care: they identify or reach out to individuals who were recently diagnosed or are out of care or having problems managing a chronic illness, follow up if patients miss appointments or show deteriorating health status based on clinical measures, and prepare and support patients in managing their disease. Such navigators receive HIPAA training, participate in team meetings, and have access to medical

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<sup>8</sup> As stated in FOA PL15-1502.

<sup>9</sup> What is a Patient Navigator? Webpage of the Patient Navigator Training Collaborative, a group that provides training for independent patient navigators who work as consultants to patients and families. See <http://patientnavigatortraining.org/>



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information that supports their work, including at least part of the patient’s electronic health record (EHR).<sup>10</sup> Sometimes they report their activities through the EHR.

Rarely is the navigator’s role limited to educating patients about how to obtain timely and appropriate care and move through the continuum of services. It almost always includes helping patients resolve their individual barriers to care. This requires building trust and credibility, providing emotional support, sharing their own experiences if they are peers, and combining these supportive roles with knowledge and skills related to the patient’s disease and available services. Many programs believe it is this combination of roles that makes community navigators so valuable.

The following roles and tasks appear in many descriptions of navigators for cancer, diabetes, HIV, and other chronic illnesses:

- Identify individuals who are newly diagnosed, out of care, experiencing delays in diagnosis or treatment, missing appointments, or not adopting health behaviors needed for successful disease self-management.
- Link—or relink—patients to health care systems.
- Help to coordinate health care, guiding patients along the continuum of health care and ensuring supportive services appropriate to their needs and specific disease (e.g., making medical appointments, accompanying the client to appointments where necessary, identifying and eliminating delays in diagnosis or treatment, and interacting with the medical team to keep them informed of the patient’s barriers, challenges, and needs).
- Help the patient prepare for medical visits, identify questions and concerns for discussion with the clinician, and communicate effectively with medical professionals.
- Access clinical-related resources and services.
- Identify enabling or supportive services such as housing, food, elder or child care.
- Provide emotional support and encouragement.
- Work with family members.
- Assist with health insurance paperwork or access to medical assistance.
- Provide or arrange transportation.
- Provide health education that is tailored to the client and designed to affect health-related attitudes and behaviors and support disease self-management—includes information about the disease and help in understanding treatment options presented by clinical providers.
- Identify and resolve other barriers to care.

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<sup>10</sup> “The Utilization and Role of Peers in HIV Interdisciplinary Teams: Consultation Meeting Proceedings,” HIV/AIDS Bureau, October 2009. An excellent overview on the use of patient navigators in HIV and the lessons from PN programs addressing other diseases. Strong focus on use of peer community health workers as navigators. See <http://hab.hrsa.gov/newspublications/peersmeetingsummary.pdf>

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These tasks are quite similar to the duties listed for CHWs, a job that received recognition with an official occupational classification code (1-1094) from the Department of Labor, Bureau of Labor Statistics (BLS). While most community navigators might be described as CHWs, not all CHWs serve as navigators. Sometimes their responsibilities involve a specific component of the health care continuum (e.g., outreach, screening, or linkage to care), and often they work briefly with large numbers of clients, rather than intensively with a much smaller number.

### **Duties of Community Health Workers: Standard Occupational Classification<sup>11</sup>**

- Assist individuals and communities to adopt healthy behaviors.
- Conduct outreach for medical personnel or health organizations to implement programs in the community that promote, maintain, and improve individual and community health.
- Provide information on available resources.
- Provide social support and informal counseling.
- Advocate for individuals and community health needs.
- Provide services such as first aid and blood pressure screening.
- May collect data to help identify community health needs.
- Excludes “Health Educators.”

**Roles community navigators should not play:** Some medical professionals, particularly those involved in cancer treatment, have identified roles they believe navigators who are not health care professionals should not play. Here is the list from a cancer-focused patient navigation paper:

- “Provide physical assessments, diagnoses, or treatments
- Order care, treatments, or medications
- Attend to or become involved in any direct patient care (e.g., changing dressings, providing direct financial assistance, picking up patients for appointments)
- Provide physical, occupational, or speech therapy
- Offer opinions about any aspect of health care delivered within or external to the organizations
- Provide recommendations or opinions about physicians or health care organizations”<sup>12</sup>

Other patient navigation experts do not fully agree with this list. For example, some PN programs ask their navigators to address transportation barriers and, with proper insurance

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<sup>11</sup> See the Bureau of Labor Statistics, Standards Occupational Classification 21-1094, Community Health Worker, at <http://www.bls.gov/soc/2010/soc211094.htm>

<sup>12</sup> Quality Patient Care, The Patient Navigator, on the website of Patient Navigation in Cancer Care, previously referenced. See <http://www.patientnavigation.com/the-patient-navigator?LMenuId=101>

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and other arrangements, to accompany their clients to medical appointments—which may include either driving them to their appointments or taking public transportation with them. Some programs also expect their navigators to serve as patient advocates, which may mean informing supervisors of problems with the services their clients receive. Diabetes navigators may help their clients monitor their glucose levels. An essential aspect of PN program planning is decision making about required, optional, and forbidden navigator roles and activities.

**Barriers to care:** Identifying and resolving individual barriers to care is one of the most important functions of navigators, and is best carried out by navigators who are similar to their clients in culture and personal characteristics. The following barriers are frequently mentioned in PN program descriptions and studies:<sup>13</sup>

- Financial (e.g., low income, uninsured or underinsured status, lack of sick leave)
- Language and cultural (e.g., limited English proficiency, cultural views about disease, stigma within the cultural group)
- Communication (e.g., limited literacy, lack of familiarity with medical terms, discomfort with asking questions of clinicians, limited time with the clinician)
- Health care system and providers (e.g., fragmentation and lack of continuity/linkages, lost test results, poor communications among providers, lack of provider cultural competence, bias and discrimination based on race/ethnicity/age, multiple gatekeepers, lack of enabling services such as transportation and child or partner care)
- Psychological (e.g., fear, distrust of medical system)
- Community (e.g., stigma, lack of attention to low-income residents)

Addressing barriers to care requires a variety of skills and activities, as well as the ability to establish trust and credibility with the client. This is often easier when the navigator comes from the same cultural community as the client, and when the navigator is a peer—someone with similar life experiences, which usually includes living with the same disease.

### Initial Use and Growth of Patient Navigation

The first structured patient navigation program in the United States was established in 1990 at the Harlem Hospital Center in New York City by Dr. Harold P. Freeman to serve low-income breast cancer patients. As Director of Surgery starting in 1979, he had been shocked at the high proportion of low-income patients who came for surgery with advanced stage breast or cervical cancer. Early detection improved after free mammography and cervical cancer screening centers were established in the community, but many women with abnormal screening results still did not receive timely diagnosis and treatment. In 1988-89, as National President of the American Cancer Society (ACS), Dr. Freeman held national hearings in seven cities, focusing on low-income people with cancer. These discussions led to a *Report to the Nation on Cancer in*

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<sup>13</sup> See especially: Harold P. Freeman Patient Navigation Institute, at <http://www.hpfreemanpni.org/our-model/?PHPSESSID=d653dac90d1dae93fc2ab8ee571a703e> and Patient Navigation in Cancer Care, at <http://www.patientnavigation.com/what-is-patient-navigation>

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*the Poor*, which highlighted the difficulties faced by low-income people—across racial and ethnic lines—in accessing health care.<sup>14</sup> He found that the Harlem Hospital experience was repeated nationwide.

Dr. Freeman coined the term “patient navigation” and developed the first PN model for addressing access to care issues. His program was designed primarily to reduce the time between an abnormal screening result and diagnosis, and from diagnosis to entry into treatment, for low-income women with breast cancer. It had two components: free or low-cost screening (examinations and mammograms) and patient navigation. Results were dramatic:

- From 1964 to 1986, 606 low-income women with breast cancer were treated at Harlem Hospital Center. Half had no health insurance. Just 6% had stage I disease, 49% had stage III or IV disease, and the five-year survival rate was 39%.
- From 1990 to 1995, 325 low-income patients with breast cancer were treated and provided with patient navigation services. A total of 42% had early stage cancer (stage 0 or I), while 21% had stage III or IV disease, and the five-year survival rate was 70%.<sup>15</sup>

These results created immediate interest in PN programs as a means of reducing disparities in medical care and outcomes, first for cancer and then for other chronic diseases and for disease prevention.

**Cancer Care:** The original Harlem Hospital PN program was soon expanded to follow cancer patients through screening, diagnosis, treatment, follow up, and survivorship. The Center to Reduce Cancer Health Disparities (CRCHD) was established within the National Cancer Institute (NCI) in 2001. One of its mandates is to “help reduce the unequal burden of cancer in our society.”<sup>16</sup> In 2005, Congress passed and President George W. Bush signed the Patient Navigator, Outreach, and Chronic Disease Prevention Act (HR 1812). It supported a demonstration program to “improve health care outcomes for people with cancer and/or other chronic diseases by helping them make their way through the health care system.” It also provided funding to “health centers and other health care facilities to develop programs that rely on non-medical health workers as navigators to help patients learn about their disease, get screening and treatment as needed, and make use of services that will help them stay healthy and live longer.”<sup>17</sup> From 2005-2010, NCI’s Patient Navigator Research Program, with funding from the National Cancer Society, supported five-year demonstration grants to nine sites to design, implement, and evaluate “a generalizable patient navigation program targeting

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<sup>14</sup> Summary of *Report to the Nation on Cancer in the Poor*, Wiley Online Library, *CA: A Cancer Journal for Clinicians*, Volume 39, Issue 5; Article first published online: 31 DEC 2008. See

<http://onlinelibrary.wiley.com/doi/10.3322/canjclin.39.5.263/pdf>

<sup>15</sup> See “The Doctor who Championed Patient Navigation in Harlem,” at the ASCO Post. In-depth interview with Dr. Harold P. Freeman. See <http://www.ascopost.com/issues/february-15,-2013/the-doctor-who-championed-patient-navigation-in-harlem.aspx>

<sup>16</sup> See National Cancer Institute website, <http://www.cancer.gov/aboutnci/organization/crchd>

<sup>17</sup> Patient Navigator Outreach and Chronic Disease Prevention Demonstration Program, as described on the Health Resources and Services Administration (HRSA) website. See <http://bhpr.hrsa.gov/nursing/grants/patientnavigator.html>

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vulnerable populations.”<sup>18</sup> Demonstration programs addressed breast, cervical, colon/rectum, and/or prostate cancer in more than 10,500 predominantly racial/ethnic minority patients with public insurance or no insurance. An evaluation found that “Patient navigation demonstrated a moderate benefit in improving timely cancer care. These results support adoption of patient navigation in settings that serve populations at risk of being lost to follow-up.”<sup>19</sup>

**Diabetes Care:** The American Diabetes Association strongly supported passage of the 2005 Patient Navigator legislation, noting that diabetes has a disproportionate impact on racial and ethnic minorities and medically underserved communities, and that patient navigators “are in a unique position to help direct individuals with diabetes to the tools and services they need to properly manage their disease.”<sup>20</sup> The Robert Wood Johnson Foundation’s Diabetes Initiative played an important role in expanding use of PN in diabetes care. Its purpose was to “assist people with diabetes to manage their own health care by providing the clinical and community support and resources they needed.”<sup>21</sup> From 2002-2009, the Foundation supported two related programs: Advancing Diabetes Self-Management, which focused on activities within clinic settings, and Building Community Supports for Diabetes Care, which focused on expanding support for diabetes management outside the clinic, through clinic/community partnerships. A total of 14 project sites were funded. Many used CHWs to help people with diabetes manage their disease through providing support, education, advocacy, and other assistance. The programs showed positive results, including both improved disease control and cost-effectiveness. Holyoke Health Center in Massachusetts, one of four sites that used CHWs as patient navigators, is profiled in a detailed chart in Chapter 5 of this guide. Its navigators from the community, including peers, proved very effective in helping diabetics keep their medical appointments and improve management of their disease, and could be similarly important in helping individuals at high risk for diabetes adopt lifestyle changes to prevent diabetes.

**HIV Services:** Peers have a long history of engagement in HIV prevention and care. That involvement has grown into navigation programs that typically involve peers or individuals at high risk for HIV. Harlem Hospital used navigators in many infectious disease programs; by the early 2000s this included HIV. The Kansas City Free Health Clinic began training Peer Educators in 2000 and began making them a part of its interdisciplinary teams in 2002.

Between 1993 and 2009, the Ryan White HIV/AIDS Program’s Special Projects of National Significance (SPNS) funded six different peer-focused initiatives.<sup>22</sup> Most peers were engaged to do outreach and provide other assistance to people living with HIV or AIDS (PLWH); some

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<sup>18</sup> National Cancer Institute Patient Navigation Research Program: methods, protocol, and measures. *Cancer*, 2008 Dec 15; 113(12):3391-9. See <http://www.ncbi.nlm.nih.gov/pubmed/18951521>

<sup>19</sup> “Impact of patient navigation on timely cancer care: the Patient Navigation Research Program,” *Journal of the National Cancer Institute*, 2014 Jun 17; 106(6). See <http://www.ncbi.nlm.nih.gov/pubmed/24938303>

<sup>20</sup> “Patient Navigator” Legislation will Help Expand Access to Diabetes Prevention and Care.” See <http://www.diabetesincontrol.com/contact-us/2933->

<sup>21</sup> The Diabetes Initiative: An RWJF National Program. Includes a variety of studies and reports. See <http://www.rwjf.org/en/library/research/2010/04/the-diabetes-initiative.html>

<sup>22</sup> “The Use of Peer Workers in Special Projects of National Significance Initiatives, 1993 – 2009. See [http://hab.hrsa.gov/abouthab/files/spns\\_useofpeersreport.pdf](http://hab.hrsa.gov/abouthab/files/spns_useofpeersreport.pdf)

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carried out system navigation tasks. Use of peers and other community members as navigators for PLWH has become very common. At least half the grantees funded under three recent SPNS initiatives use navigators, often as members of multidisciplinary teams:

The SPNS-funded peer program at Kansas City Free Clinic “involves facilitation of weekly support groups, direct contact with doctors and pharmacists, and participation on multidisciplinary teams.”

-- La Trischa Miles, Peer

- The *Enhancing Access for Women of Color Initiative* supported innovative models for helping women of color access and remain in HIV care using community-based outreach, patient education, intensive case management, and patient navigation strategies. Most of the ten grantees engaged navigators (often called peers, *promotores*, or community health workers). The Core Foundation in Chicago based its HIV navigator program on Dr. Freeman’s Harlem Hospital model for breast cancer care.<sup>23</sup>
- *The Building a Medical Home for Multiply Diagnosed HIV-positive Homeless Populations Initiative*, which began in 2012, includes nine program grantees. A majority report program models that include peer navigators or similar personnel.<sup>24</sup>
- *The Systems Linkages and Access to Care Initiative* is funding six projects that integrate different components of the public health system “to create new and effective systems of linkages and retention in care for hard-to-reach populations who have never been in care, have fallen out of care or are at-risk for falling out of care.” Four of the six grantees are using peers in some type of navigator role, describing them as peer coordinators, peer linkage specialists, nurse/peer teams, or HIV-positive and high-risk negative recruiters.<sup>25</sup> One of the navigation projects, operated by the Virginia Department of Health, is profiled in Chapter 5 of this guide.

Peer navigation is a commonly used strategy in Early Intervention Services (EIS), a core medical-related service for Ryan White HIV/AIDS Program (RWHAP) care and treatment programs under Part A (funding to metropolitan areas with high rates of HIV) and Part B (funding to the states). EIS encompasses HIV diagnosis, linkage to care, and retention to care. EIS programs must include four components: HIV Testing and Targeted counseling, referral services, linkage to care, and health education and literacy training that enable clients to navigate the HIV system of care.<sup>26</sup> EIS programs help newly diagnosed PLWH enter and previously diagnosed PLWH re-enter care, often using navigators to help at all stages including retention in care.

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<sup>23</sup> See the SPNS website description of the Enhancing Access for Women of Color Initiatives, at <http://hab.hrsa.gov/about/hab/special/womencolor.html>, or What’s Going on @ SPNS April 2011 newsletter, at <http://hab.hrsa.gov/about/hab/files/spnswomencolorapr2011.pdf>

<sup>24</sup> See the SPNS website description of the Building a Medical Home for Multiply Diagnosed HIV-positive Homeless Populations Initiative, at <http://hab.hrsa.gov/about/hab/special/homeless.html>

<sup>25</sup> See the SPNS website description of the Systems Linkage and Access to Care Initiative at <http://hab.hrsa.gov/about/hab/special/systemslinkages.html#a> or the Systems Linkage Initiative website at <http://hivlinkage.ucsf.edu/>

<sup>26</sup> See Ryan White HIV/AIDS Program, National Monitoring Standards for Ryan White Part A Grantees: Program – Part A, Section B, at <http://hab.hrsa.gov/manageyourgrant/files/programmonitoringparta.pdf>

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**Other Diseases:** The navigation models used in breast cancer, diabetes, and HIV have also been adapted for use in diagnosing, treating, and managing many other diseases. For example, navigators have been used to help patients control blood pressure, asthma, chronic kidney disease, and cardiovascular disease. Studies have shown that community navigators can also improve health outcomes in prenatal care, smoking cessation, child and adult immunizations, and depression management.<sup>27</sup>

As the use of patient navigation has increased, so has the availability of training programs, training modules and curriculum, and nonprofit organizations supporting and assisting navigators and the health care providers that employ them.

### Current Status of Patient Navigation

“Patient navigation, which includes community health workers and clinically licensed navigators such as nurses and social work navigators, has begun to play a critical role in the continuum of care.”

– George Washington University Cancer Institute (based on research announced December 23, 2013)

Patient navigation is now a valued component of the health care system. The number of hospitals, clinics, and other health-related organizations with PN programs is growing rapidly. PN programs are now the norm for cancer treatment facilities, increasingly common in diabetes treatment programs, and becoming a desirable mechanism for management of other chronic diseases. The use of patient navigators (many of them peers) is now widespread in HIV services. PN programs may become mandatory in some settings and their use is growing in others. For example:

- The Cleveland Clinic is now using navigators for diseases including diabetes, hypertension, and chronic kidney disease.<sup>28</sup>
- As of 2013, the American Cancer Society had patient navigators in 125 hospitals, treatment centers, and other health care settings throughout the country.
- As of January 2015, the American College of Surgeons (ACoS) Commission on Cancer (CoC) will not accredit a cancer center unless it has a navigator program in place. More than 1,500 hospitals in the U.S. are CoC accredited. They represent 30 percent of all hospitals, but serve more than 79 percent of all new cancer cases diagnosed annually.<sup>29</sup>

There is no national certification of patient navigators, but a growing number of states provide for training and certification. The growth of PN programs has been assisted by the growing number of organizations that train navigators, the increasing availability of training curricula, and the development of nonprofit associations that support and advocate for the profession of

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<sup>27</sup> Samantha Hendren et al., “Study Protocol: A randomized controlled trial of patient navigation-activation to reduce cancer health disparities.” *BMC Cancer*, 2010; published online October 13, 2010. See <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2964637/>

<sup>28</sup> “Patient Navigators Find Role in Local Health Care System,” *Cleveland Plain Dealer*, October 8, 2012. See [http://www.cleveland.com/healthfit/index.ssf/2012/10/patient\\_navigators\\_find\\_role\\_i.html](http://www.cleveland.com/healthfit/index.ssf/2012/10/patient_navigators_find_role_i.html)

<sup>29</sup> Frequently Asked Questions (FAQ) from the Harold P. Freeman Patient Navigation Institute. See <http://www.hpfreemanpni.org/fag/>

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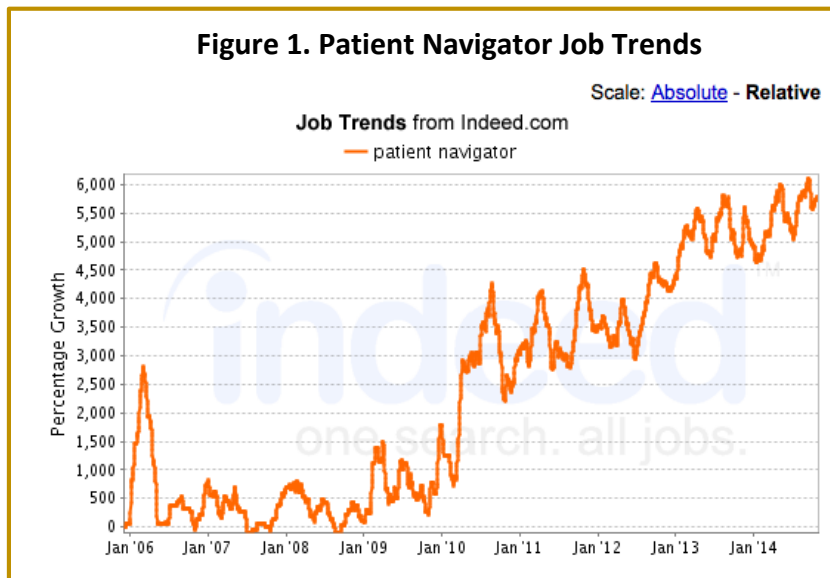
community health workers, train navigators, and encourage the use of both community and medical professional navigators. A variety of training opportunities are available from varied entities. For example:

- **University Continuing Education Schools:** Georgetown University's School of Continuing Studies in Washington, DC offers a three-course, 48 hour certificate program in patient navigation. It is open only to individuals with a Bachelor's degree or equivalent. The courses include Patient Navigation Fundamentals, Building the Patient-PN Partnership, and Developing the Patient Navigator Skill Set, and involve interactive exercises along with classroom learning. The cost in 2015 was about \$3,000.
- **Community Colleges:** Gateway Community College in New Haven, Connecticut offers Community Health Worker training at no cost through its Accelerating Connection to Employment (ACE) Program, funded by the U.S. Department of Labor and the Annie E. Casey Foundation. Training focuses on communication skills, interpersonal skills, confidentiality skills, knowledge of the community, organizational skills, and knowledge base of health.
- **Area Health Education Centers (AHECs):** In Massachusetts, the Central Massachusetts AHEC provides a 15-session, 45 hour Patient Navigator course for which college credit is available. Focus is on a combination of occupational competencies (e.g., Communications, Cultural Competence and Responsiveness), and Health and Disease-Specific Competencies (e.g., Cardiovascular Health and Cardiovascular Disease). The AHEC of Southwestern Massachusetts offers two-day PN Supervisory Training, with continuing education units (CEUs) available.
- **Nonprofit organizations:** The Harold P. Freeman Patient Navigation Institute, founded in 1990 to support patient navigation training to individuals associated with organizations, provides an intensive two-day in-person or self-paced online training program that includes ten modules plus practicum (patient interaction) and case studies. The course focuses on cancer as the primary disease, but is applicable to other chronic diseases. The cost as of 2015 was \$995 per person; graduates receive a certificate and become part of an alumni network.



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Patient navigators now serve the full spectrum of patients. The complexity of the health care system is a concern for many Americans who are not poor, uninsured, racial or ethnic minorities, or otherwise subject to disparities in health care. PN programs now serve the broader population, and often target groups such as women, children, and the elderly. Navigators are frequently employed by hospitals or other treatment facilities, but today many work independently, and are hired to assist individual patients and their families in dealing with



the health care and broader social services and entitlements systems. Often these navigators call themselves Patient Advocates or Health Advocates. Many navigators working as private consultants have completed certificate programs at universities or community colleges or been trained by for-profit or nonprofit entities. Their education and training are extremely varied. Many have post-secondary degrees but most do not have a health care background.

Many are networked through professional associations like the National Association of Healthcare Advocacy Consultants (NAHAC) or the Alliance of Professional Health Advocates (APHA).

According to the Patient Navigation Blog, there was a 6,000 percent increase in the number of patient navigator jobs from January 2006 to January 2012 (See Figure 1).<sup>30</sup> A growing proportion of navigators are independent navigator consultants.

One possible emerging group of navigators is medical interpreters, who refer to themselves as Patient Guides. The Cross-Cultural Health Care Program, an international nonprofit with a long history of training medical interpreters, has begun a Patient Guides Training Program designed to prepare trained, experienced, professional medical interpreters to serve as navigators, connecting patients to “all points of service.” Many interpreters come from the community, and have the obvious advantage of being able to serve limited-English-proficient patients in their native language and native English speakers in English. The 24-hour training session costs about \$500; training of trainers is also available.<sup>31</sup>

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<sup>30</sup> See Patient Navigation Blog, at <http://www.patientnavigationblog.com/2014/12/patient-navigtion-looks-ahead.html>

## Checklist of Roles Community Navigators Play

The chart below summarizes roles reported for navigators from the community, as described in reports, studies, and assessments of PN programs focusing on specific diseases. It shows that navigator roles are quite similar across disease programs. Use the last column to identify roles patient navigators should play in your program.

Roles Navigators Play: Based on Disease Focus				
Role	Cancer	Diabetes	HIV/AIDS	Your Program
Outreach for testing/screening	✓		✓	
Prevention education/counseling			✓	
Outreach to out-of-care individuals		✓	✓	
Movement from abnormal/positive test to timely diagnosis/confirmatory testing	✓		✓	
Movement from diagnosis to timely treatment	✓	✓	✓	
Entry/re-entry into disease-specific medical care	✓	✓	✓	
Enrollment in disease control activities		✓	✓	
Assistance in scheduling/keeping medical appointments	✓	✓	✓	
Assistance in accessing other needed medical-related services	✓	✓	✓	
Assistance in obtaining needed social services	✓	✓	✓	
Coordination of services	✓	✓		
Transportation assistance	✓	✓	✓	
Preparation for effective communication with clinicians	✓	✓	✓	
Education for disease self-management		✓	✓	
Treatment adherence support	✓	✓	✓	
Insurance – help with obtaining insurance & with paperwork	✓	✓	✓	
Identification of barriers to care	✓	✓	✓	
Emotional support/counseling	✓	✓	✓	
Disease-specific education	✓	✓	✓	
Healthy lifestyle education		✓	✓	
Review of medical records		✓	✓	
Support for family members	✓	✓	✓	
Post-treatment follow up	✓			
End of life support/assistance	✓			

<sup>31</sup> Patient Guides: A New Approach. The Cross Cultural Health Care Program. Includes information about the benefits of training medical interpreters as navigators and also describes the training program. See [http://xculture.org/wp-content/uploads/2012/10/Webinar\\_Rev\\_2BF.pdf](http://xculture.org/wp-content/uploads/2012/10/Webinar_Rev_2BF.pdf)

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Now look back over your responses and the HIV column of the chart. Note that HIV programs make the most comprehensive use of navigators. *Can you think of reasons why this is true?*

Navigators may, of course, play other roles that were not reported in these studies. *Are there other roles you expect your navigators to play? If so, what are they?*

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## CHAPTER 3: BENEFITS OF PATIENT NAVIGATORS: FOR PATIENTS, CBOs, AND THE HEALTH CARE SYSTEM

### Objectives:

- To describe direct and indirect benefits to patients from patient navigation
- To describe ways in which patient navigators benefit CBOs, including HIV prevention and care providers
- To describe benefits of patient navigators to the broader health care system
- To identify additional benefits that are likely in the future

### Overview

Patient navigation began as a model for reducing disparities in breast cancer care and overcoming barriers to care facing low-income uninsured or underinsured women, most of them African American or Latino. The desired benefits were very specific: more timely, better quality diagnosis and treatment, and higher survival rates for these patients. The scope of PN programs and the roles of navigators have expanded, and the original model has been adapted for use with many diseases. Navigation is also used to address other health-related conditions and needs, from prenatal care and childhood vaccinations to smoking cessation. Desired patient benefits reflect specific diseases and medical purposes, and for many PN programs they include increased health care access, improved care quality, and improved patient outcomes for underserved populations. In addition, patient navigation is now considered a valuable component of health care for the entire population. There are many types of patient navigation programs targeting varied populations. This chapter describes benefits—direct and indirect, immediate and longer term—of PN programs overall, but focuses on programs staffed by community navigators.

The benefits of patient navigation are often measured in disease-specific terms, such as the following:

- **For cancer**, higher rates of survival (usually after 5 years), as a result of improvements including increased screening, early detection (earlier disease stage at diagnosis), prompt diagnosis following an abnormal screening result (often less than 30 days), timely entry into culturally appropriate and high quality treatment (e.g., initiation of treatment within 60 days following diagnosis), obtaining of other services needed to maintain engagement in treatment, and follow up monitoring (regular medical examinations).
- **For diabetes**, evidence of regular medical visits (and a reduction in missed appointments), improved disease control (reduction in the average blood sugar level or A1C) and self-management, a healthier lifestyle (e.g., improved nutrition and exercise), reduced hospitalizations, and reduced health care costs.

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- **For HIV**, improvements all along the HIV continuum of care/treatment cascade: reduced transmission of HIV and fewer HIV-related deaths within the community, and evidence of timely screening and diagnosis (reduced percent of concurrent HIV and AIDS diagnosis or AIDS diagnosis within 12 months after initial diagnosis), prompt linkage to/entry into care (within 90 days after diagnosis), retention in care (for example, at least one medical visit every 6 months over a 24-month measurement period, with a minimum of 60 days between medical visits), prescriptions for/use of anti-retroviral therapy (ART), and positive health outcomes (especially viral load suppression) for HIV-positive individuals.

Regardless of the specific disease or health condition and the specific desired health outcomes and related performance measures, community navigators can contribute to the following broad health-related benefits:

- **Disease prevention:** Fewer new cases of a disease are reported as a result of changes in lifestyle and reduction in risky behaviors.
- **Screening and early detection:** Regular or routine screening, especially of individuals considered to be at high risk, which can improve treatment success and survival rates.
- **Prompt diagnosis:** Individuals with an abnormal screening result or a positive test result obtain a confirmatory test or further diagnosis promptly, without delays due to costs or other access issues.
- **Access to care:** Following diagnosis, patients promptly begin receiving needed medical, medical-related, and social services; service providers have the skills and the cultural competence to meet patient needs.
- **Retention in care:** Patients complete their treatment regimens and continue regular medical visits for chronic illnesses, which helps them avoid complications and hospitalizations and contributes to improved health status.
- **Improved health status:** Patients achieve positive clinical outcomes appropriate to the disease; patients see themselves as healthier and more able to carry out tasks of daily living.
- **Increased survival rates:** Patients are more likely to be alive 5 or more years after diagnosis.

Each of these performance and outcome measures can be seen as a direct benefit to patients, CBOs, the health care system, and the community.

**Potential community-level benefits:** The most important long-term community benefit of patient navigation is expected to be improved population health (including reduced disparities across population groups), which contributes to other economic and social benefits. These benefits include the following:

- **Prevention:** Reduction in the number of new cases of specific diseases (e.g., HIV and diabetes).
- **Mortality:** Reduced deaths from various diseases.

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- **Health status:** An increase in the proportion of residents who report good health, with chronic diseases under control.
  - **Lifestyles:** More residents with healthy lifestyles (e.g., healthy nutrition, regular exercise).
  - **Economics:** Financial and economic benefits such as low absenteeism from jobs and reduced health care costs for employers, individuals, medical facilities, and the government, as well as increased competitiveness in attracting business and industry when a city is known for having a high performing health care system and inclusive services; increased use of navigators also means creation of new jobs.

While it is not yet feasible to document such benefits at a community level or to determine what proportion of such benefits result from patient navigation, many studies have identified and measured specific benefits among defined groups of patients, and compared measures for patients with and without patient navigators. Overall, most researchers believe that well designed and implemented patient navigation programs contribute to positive health outcomes.

**Health disparities:** Similar health benefits are desired for all patients, and a key long-term hoped-for benefit of PN is to reduce disparities in health care access, care, and outcomes. Community PN programs focus on helping low-income, uninsured or underinsured, racial/ethnic/cultural minorities, and other underserved populations achieve *not only good health outcomes but the same health outcomes* as people who are moderate or high income, insured, and receive regular preventive care and treatment of medical problems.

Studies suggest that the benefits of PN services are most likely to occur when navigators have personal, face-to-face interactions with clients, not merely telephone contacts, and when the navigators are “housed and organized” with care providers.<sup>32</sup>

## Benefits to Patients

Patients who receive assistance from well designed, well managed PN programs experience both direct and indirect benefits. Many of the direct benefits result from help in entering and moving through the system of health care to address a life-threatening illness and/or chronic condition. For low-income, uninsured or underinsured individuals who are often underserved or poorly served in the health care system, equally important is the help they receive in addressing barriers to care. Studies show that patients assisted by community navigators often obtain the following benefits:

- **Personal support:** Having continuing access to a person to provide information and support is one of the most valued benefits of patient navigation for underserved populations. Patients with life-threatening illnesses but little experience navigating the

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<sup>32</sup> Karen Freund, “Patient Navigation: The Promise to Reduce Health Disparities,” *Journal of General Internal Medicine*(2): February 26, 2011, 110–112, published online December 15, 2010. See <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3019331/>

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health care system, often facing other personal and institutional barriers to care, now have someone they can trust, a person who is familiar with the maze of services, understands their fears and concerns, and is available when needed to provide personalized information, assistance, and emotional support. One navigator study noted that “patient navigation tasks targeted at supporting specific patients seem to be the most effective at helping patients find appropriate care.”<sup>33</sup>

- **Access to screening and prompt diagnosis:** When navigators do community outreach, the people they contact learn that free or low-cost screening is available, and receive help in getting screened. If the test is positive or results are abnormal, they are able to obtain needed diagnostic services promptly even if they have no regular source of primary care, limited or no insurance (or no idea how to obtain authorization for further diagnostic tests from Medicaid or private insurer), and no idea where to go for services. With help from a navigator, they access services promptly and are supported in making and keeping appointments and dealing with family responsibilities or other factors that might otherwise delay services.
- **Understanding of the disease:** Patients often look to navigators for basic information about their disease and how to live with it. Navigators provide information, locate resources in an appropriate language and literacy level, and—if they are peers with the same disease or condition—share their experiences after being diagnosed with the disease and why it is so important to seek care immediately. If the patient needs more extensive information about the disease, the navigator can identify a nurse or other knowledgeable clinician to answer questions and emphasize the need for immediate treatment.
- **Access to appropriate care:** Navigators help patients find and access affordable, high quality, culturally appropriate medical care. Patients benefit from entering care promptly and from having a medical caregiver and other service providers that are a good “fit.” Prompt entry into care has major benefits in terms of the increased likelihood of long-term survival and the reduced likelihood of medical complications and damaged health.
- **Retention in care:** Patients with navigators are more likely to receive needed services beyond medical care—including other medical-related services (e.g., mental health, substance abuse, dental care). They are also more likely to receive enabling or “wraparound” services like transportation or a food bank. They are more likely to remain in care because of the individualized support of the navigator and the knowledge provided about the importance of regular care and adherence to treatment.

In the Fenway Institute’s SPNS-funded HIV System Navigation Program, navigators served as “personal coaches, who help [individuals] develop the skills, knowledge, and connections necessary to stay in care.”

-- Judith Bradford, former Assistant Project Director<sup>34</sup>

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<sup>33</sup> Sona Thakkar, “What about Patient Navigation Makes it Work?” November 14, 2013. See [https://accrualnet.cancer.gov/communities/conversation/what\\_about\\_patient\\_navigation\\_makes\\_it\\_work#.VRHNpfnF\\_YE](https://accrualnet.cancer.gov/communities/conversation/what_about_patient_navigation_makes_it_work#.VRHNpfnF_YE)

<sup>34</sup> Described in “The Utilization and Role of Peers in HIV Interdisciplinary Teams,” previously referenced.

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- **Disease self-management:** Navigators help patients learn to manage their disease and prevent complications and hospitalization. They receive information and assistance that encourages them to take medications regularly, make lifestyle changes related to diet and exercise, and join peer groups. They benefit from knowing how to obtain services like mental health counseling or support groups that will help them stay healthy. They learn how to live well with the disease. This has been especially well documented in diabetes-focused PN programs.
  - **Positive health outcomes:** All navigator services are designed to lead to positive health outcomes for the patients they assist. That may mean viral suppression for people living with HIV, cures for life-threatening illnesses, long-term survival for cancer patients, and disease control for diabetics.

The work of navigators in identifying and resolving the barriers to care of individual patients also leads to other, less direct benefits. For example:

- **Medical home:** As part of their treatment, low-income patients are often linked to an FQHC or other safety-net clinic that becomes their medical home. They and their families now have a regular source of primary medical care, including preventive and treatment services. FQHCs are accessible regardless of the ability to pay and generally provide culturally and linguistically appropriate services—which makes patients comfortable obtaining care.
- **Attitude and behavior change:** Patients who previously did not seek medical care due to shame, stigma, distrust of the health care system, fears related to immigration status, or other personal or cultural factors receive information and support from navigators that can lead to changes in beliefs and attitudes. They become comfortable seeking care and communicating with providers to get what they need.
- **Increased satisfaction:** Navigation often leads patients to report increased satisfaction with their caregivers and service providers. They may also report an improved quality of life.

These benefits help to reduce health disparities. They occur because, as one study indicated:

“Patient navigators can not only facilitate improved health care access and quality for underserved populations through advocacy and care coordination, but they can also address deep-rooted issues related to distrust in providers and the health system that often lead to avoidance of health problems and non-compliance with treatment recommendations. By addressing many of the disparities associated with language and cultural differences and barriers, patient navigators can foster trust and empowerment within the communities they serve.”<sup>35</sup>

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<sup>35</sup> Ana Natale-Pereira, MD, MPH, et al., “The Role of Patient Navigators in Eliminating Health Disparities,” *Cancer*, August 2011:117 (15 suppl). See <http://www.ncbi.nlm.nih.gov/pubmed/21780089>



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## Benefits to Community-based Organizations

The benefits to patients from PN programs are generally also benefits to CBOs—FQHCs, other safety-net clinics, and providers of other medical-related and/or social services, including case management, that are located in the community—because the mission of such CBOs is usually to help their patients/clients receive needed services and achieve positive outcomes.<sup>36</sup> In addition, CBOs are often the most accessible components of the health care and supportive services system, and they often face challenges in helping their clients obtain a full range of needed services, particularly medical specialty care. Community navigation programs help CBOs establish and maintain organizational relationships and better serve their clients. CBOs that operate PN programs, often in collaboration with hospitals and other service providers, are likely to achieve benefits such as the following:

- **Better linkages with hospitals and other clinical providers:** There is growing support for PN programs among hospitals and other treatment providers, although their own programs may not be staffed by community navigators. With health care reform and the growing focus on Patient Centered Medical Homes (PCMHs) that coordinate care for their patients, these other health care providers recognize the need for improved communications, data sharing, and cross-referrals. With appropriate relationship building, community navigators from the CBO become valuable to these other providers, helping them to meet performance measures. This helps to strengthen ongoing linkages between CBOs and the rest of the health care system.
- **Improved coordination of care** for CBO clients. Navigators maintain relationships with multiple medical and social service providers and focus specifically on ensuring that their clients receive timely, coordinated services. Medical case managers play a related role and may help to train—and sometimes supervise—navigators. Case managers typically have large caseloads and limited time to spend with each client. They seldom are able to accompany them to medical intake or appointments. They benefit from the extra person power navigators provide, and their focus on making sure clients get the services they need.
- **Improved service outcomes** for their clients, because of the increased attention to medical-related and support service access and care coordination. FQHCs are concerned with meeting performance measures established by the federal Bureau of Primary Health Care (BPHC), and most other providers have standards of care, quality improvement plans, and performance measures. Navigators help them meet these standards and performance goals.
- **More efficient use of staff time**, especially where navigators are fully integrated into interdisciplinary teams. Navigators benefit from regular guidance, other staff are kept

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<sup>36</sup> While most medical providers refer to the people they assist as *patients*, non-medical providers often use the term *client*. This guide uses the two terms interchangeably since CBOs with PN programs may be either medical or non-medical providers.

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informed about client needs, and all are better able to spend their time on tasks appropriate to their training. Studies have shown that clinical staff may initially resist the inclusion of navigators in a clinical team, but once they have positive experiences with navigators, they begin to rely on them to keep them informed about patients and ensure that they obtain access to needed services.<sup>37</sup>

“Doctors at Fenway Institute recognize peers as extenders of medical services and appreciate the fact that peers often elicit important information from clients that they are less inclined to share with their clinicians.”

– Dan Aguilar, peer interventionist, Fenway Institute, Boston<sup>38</sup>

- **Low-cost/high return:** Many CBOs are experiencing a growing demand for their services. While clinical providers in states that have expanded Medicaid are likely to have a higher proportion of insured clients, they often struggle to maintain adequate staffing. Community navigators should receive fair and competitive wages and benefits, but they are less expensive than Registered Nurses or social workers. Appropriately selected, trained, and supervised, they can fill numerous important roles at a very reasonable cost—a considerable benefit for CBOs, for whom costs are always a concern.
- **Higher patient satisfaction:** Navigation programs generally report increased patient satisfaction because of the often intensive personal assistance patients receive from navigators who are culturally competent and committed to resolving barriers to care. Some CBOs are now competing for insured clients and doing their best to retain clients who now have multiple options for care. The higher the patient satisfaction, the more likely insured clients are to continue seeking care from CBOs.
- **Better linkages with the community:** There is usually strong community support for the employment of community health workers and peers by health and social service agencies. The concept of patient navigation is generally strongly supported as well. Most residents have some personal experience with the challenges of obtaining timely, high quality health care and know how hard it can be to finding their way through the complex system of care. Underserved communities are generally aware of disparities in health care. Navigation programs demonstrate to the community the CBO’s commitment to hire residents and to provide needed personal support to their clients.
- **Opportunity for additional income:** Most services provided by navigators are not yet reimbursable by Medicare or by Medicaid in most states. However, this is changing. Recent federal guidelines have opened the door for some preventive services to be provided by non-licensed providers under the supervision of professional practitioners, and Affordable Care Act-funded State Health Homes and Innovation Models frequently
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<sup>37</sup> “The Utilization and Role of Peers in HIV Interdisciplinary Teams,” previously referenced.

<sup>38</sup> *Ibid.*

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include CHWs in navigator roles.<sup>39</sup> In addition, some Medicaid Managed Care Organizations (MCOs) fund FQHC navigation programs because of their value in helping hard-to-serve patients (including PLWH) remain in care.<sup>40</sup> It is likely that in the future, private insurance companies and/or Medicaid will increasingly cover and reimburse for community PN services.

## Benefits to the Health Care System

The health care system benefits from PN programs in many of the same ways as CBOs (which are a part of that system), but there are some differences in focus and perspective. Among the components of the health care system are hospitals and hospital-related clinics and specialized treatment centers, public clinics and other health facilities, private physician groups, providers of diagnostic and screening services, disease-focused treatment providers, medical-related and support service providers, and public and private insurance entities. Following are some of the benefits—direct and indirect—they receive from PN programs, particularly community PN programs targeting underserved populations:

- **Improved patient outcomes:** Medical-related providers of all types, particularly hospitals, public treatment facilities, and entities that serve low-income patients, benefit from operating or linking with CBO-based PN programs that contribute to positive patient outcomes like improved cancer survival rates, diabetes control, and suppressed viral loads for PLWH. These entities generally place great value on positive clinical outcomes for their own sake, and because they lead to other benefits, such as:
  - Increased ability to attract top clinicians and other staff
  - Enhanced external ratings and reputation
  - Improved marketing position and competitiveness
  - Increased desirability as a partner
  - Increased ability to attract both public and private funding
  - Reduced costs, including a decrease in (often unreimbursed) service costs of complex treatments and hospitalization and decreased inappropriate use of hospital emergency rooms

Positive client outcomes are an important benefit for private insurance companies and Medicaid MCOs because they reduce the costs of care. When they exceed performance standards, MCOs may receive increased reimbursements. When costs of care are lower, insurance companies may maintain current premiums or increase them less.

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<sup>39</sup> Amy Katzen and Maggie Morgan, “Affordable Care Act Opportunities for Community Health Workers,” Center for Health Law & Policy Innovation, Harvard Law School, May 30, 2014. Describes opportunities for navigators and other types of CHWs under the Affordable Care Act (ACA). See <http://www.chlpi.org/wp-content/uploads/2014/06/ACA-Opportunities-for-CHWsFINAL.pdf>

<sup>40</sup> Emily Gantz McKay, “Sustainability Models, Options, and Strategies: Preparing for a Changing HIV and Health Care Environment,” updated November 2014. Provides information on how community clinics and other CBOs are remaining sustainable under health care reform. See the EGM Consulting website, at [www.egmc-dc.com](http://www.egmc-dc.com)

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In the Bridge, a demonstration peer navigation program in Los Angeles that targeted individuals with severe mental illness, patients participating in the navigation program were compared with the “treatment as usual” (TAU) group after six months. Statistically significant differences were found. Compared to the TAU group, “participants receiving the intervention experienced fewer pain and health symptoms, and changed their orientation about seeking care to a primary care provider rather than the emergency room.”<sup>41</sup>

- **Reduced disparities in health care:** Many segments of the health care system, especially public hospitals and clinics, other safety-net providers, and federally funded treatment facilities such as cancer centers are extremely concerned about the continuing disparities in health care access and outcomes for some populations. Reductions in disparities resulting from PN programs are highly valued because of the institutional commitment to achieving equality among all populations in both services and results.
- **Low-cost/high return:** Like CBOs, other components of the health care system that run or help to pay for PN programs with community navigators benefit from moderate staff costs with a high return.
- **Increased cultural competence:** Entities that hire or collaborate with community navigators gain cultural competence, since navigators typically bring expertise in working with specific underserved populations, often including language skills. In addition, increased linkages and coordination encouraged by navigators can bring together entities within the health care system that have skills in serving different target populations. The effect is improved overall cultural competence and the ability to ensure culturally appropriate services through collaboration and cross-referrals.
- **Support for clinicians so they are more productive:** As with CBOs, other parts of the health care system that use community navigators benefit from more efficient use of clinical and other professional staff. Navigators free them for tasks that require their training while ensuring that patients receive needed supports and personalized assistance—and often provide information useful to clinicians. Navigators can also reduce burdens on social workers, case managers, and other staff.
- **Improved patient satisfaction:** Patients who receive support from navigators often express more positive feelings not only about their primary service provider but also about the entire health care system.

## Benefits Important in HIV Prevention and Care

The chart below lists documented benefits of effective PN programs, and links them to desired benefits and measures of success for HIV-focused PN navigation programs employing community navigators. Most of the benefits are similar, though they may be stated in different

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<sup>41</sup> Erin Kelly et al., “A Pilot Test of a Peer Navigator Intervention for Improving the Health of Individuals with Serious Mental Illness,” *Community Mental Health Journal*, accepted May 2013. See [http://www.integration.samhsa.gov/workforce/Brekke\\_Research.pdf](http://www.integration.samhsa.gov/workforce/Brekke_Research.pdf)

terms and are often assessed using disease-specific measures, including HRSA, CDC, and other performance measures.

<b>Benefit</b>	<b>Benefit as Applied to HIV</b>	<b>Description/Typical Measures</b>
Disease prevention	Prevention of HIV transmission	<ul style="list-style-type: none"> <li>• Reduction in new HIV cases</li> <li>• Increased percent of HIV+ people receiving anti-retroviral therapy</li> <li>• Increased number of high-risk HIV-negative individuals receiving Pre-exposure prophylaxis (PrEP)</li> <li>• Increased participation by HIV+ clients in prevention for positives programs</li> </ul>
Screening and early detection	<ul style="list-style-type: none"> <li>• Routine testing</li> <li>• Targeted testing</li> </ul>	<ul style="list-style-type: none"> <li>• Increased HIV testing in health care facilities as part of routine examinations and preventive care</li> <li>• Identification of HIV+ people through community testing that targets high-risk populations</li> </ul>
Prompt diagnosis	Early diagnosis	<ul style="list-style-type: none"> <li>• Reduced percent of late testers – individuals with a concurrent first diagnosis and AIDS diagnosis or AIDS diagnosis within 12 months after first testing positive</li> </ul>
Access to care	<ul style="list-style-type: none"> <li>• Linkage to HIV-related medical care</li> <li>• Re-linkage to HIV-related medical care</li> </ul>	<ul style="list-style-type: none"> <li>• First medical visit within 90 days of diagnosis</li> <li>• Individuals who know their status but have not been receiving HIV-related medical care</li> </ul>
Retention in care	Retention in HIV-related medical care	<ul style="list-style-type: none"> <li>• Increase in the number of identified HIV+ individuals with at least 1 HIV medical visit every 6 months over a 24-month measurement period, with visits at least 60 days apart</li> </ul>
Improved health status	Viral load suppression	<ul style="list-style-type: none"> <li>• Percent of diagnosed HIV+ individuals or program clients who have a viral load of &lt; 200 copies/mL</li> </ul>
Disease control or self-management	Treatment adherence	<ul style="list-style-type: none"> <li>• Percent of individuals prescribed ART who take it regularly</li> <li>• Reduction in opportunistic infections among program clients</li> </ul>
Reduced barriers to care	Strong connection to care	<ul style="list-style-type: none"> <li>• Reduction in missed medical appointments by clients</li> <li>• Consistent use of supportive/ enabling services by clients</li> </ul>

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## CHAPTER 4: LESSONS FROM PATIENT NAVIGATOR PROGRAMS

### Objectives:

To identify and describe:

1. Diverse PN program models, used for both HIV and other diseases
2. Core components of PN programs and core roles for community-based patient navigators
3. Factors that contribute to the success of PN programs in improving client linkage to care, retention in care, and health outcomes
4. Pitfalls and challenges facing PN programs and strategies used to avoid or address them

### Programs and Models Reviewed

The charts in Chapter 5 profile five patient navigator programs, some demonstration projects with clear start and end dates, and others ongoing. Three focus on people living with or at high risk for HIV, two on breast cancer and diabetes programs—though the models are considered appropriate for many diseases. The profiles include:

1. **Harlem Hospital Center Navigation Program, New York, NY:** The first documented patient navigation program, designed to improve breast cancer screening, reduce time delays in obtaining diagnosis and treatment, and increase survival rates among mostly low-income, uninsured African Americans and Hispanics.
2. **Proyecto Vida Saludable, Holyoke Health Center, Holyoke, MA:** A project that demonstrated the value of patient navigation in changing lifestyles and reducing complications from diabetes, and documented a navigation model applicable to other chronic diseases; population served includes many Hispanics.
3. **Patient Navigation Strategy, Virginia Department of Health (VDH), Richmond, VA:** A strategy implemented as part of a RWHAP SPNS initiative designed to improve linkage to care, retention in care, and viral suppression for people with HIV who are newly diagnosed, out of care, or in danger of falling out of care; profile includes implementation experiences at the Centra Health system, a largely rural implementation site in Lynchburg, VA.
4. **Change for Women (C4W), Christie's Place, San Diego, CA:** A linkage to/retention in care model in an organization founded on a peer-support model and established to empower women, children, and families whose lives have been impacted by HIV to take charge of their health and wellness.
5. **CareLink, Cascade AIDS Project, Portland, OR:** A PN project, run by a large non-medical provider of HIV prevention and care services, that assists HIV-positive individuals who are newly diagnosed, were recently released from jail, or have been out of medical care

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for six months or more to connect to medical care, housing, and other services; also helps partners and high-risk HIV-negative individuals obtain services to help them stay HIV-negative.

The charts in Chapter 5 provide detailed information about the characteristics of these diverse PN programs. The charts are organized so that you can easily find specific kinds of information, such as project purpose, navigator roles, job qualifications, training, supervision and support, outcome measures, success factors and challenges, and observations and/or advice from the programs, as well as reference materials and/or a contact person at the organization.

## Factors that Contribute to Success

The projects are diverse, but at least half mention the following as important factors in project implementation and success:

- **Clearly defined and communicated navigator roles.** Key roles include helping clients to navigate the system of care, including support services and working with clients to identify and address barriers to care. Most specify other roles, such as community outreach, health education, HIV treatment adherence, and development of linkages with other providers. As one project director put it, “Most patient navigators could be described as community health workers, but most community health workers are not navigators.” Role definition is very important in identifying training needs, projecting time allocations, assessing performance, and determining reasonable caseloads.
- **Careful selection of patient navigators.** Navigators should know the geographical and/or racial/ethnic community they will be serving. Three projects hire only peers living with the same disease as their clients. Life experiences similar to those of their clients is a priority. Related knowledge and experience is seen as more important to project success than formal education. Projects that require a Bachelor’s degree allow for equivalent experience instead. Good reading and writing skills and “health literacy” are important because of project reporting requirements and the need to help clients understand written materials. Navigators must have prior experience with the local health care system and social service providers. Important personal characteristics include a deep commitment to helping others and meeting project goals, as well as empathy, patience, and the ability to build and maintain trust.
- **Targeted, intensive navigator training and career development.** Most projects arrange for a combination of internal and external sessions, using available trainer training and downloads of tested curriculum modules. A few states have CHW training courses linked to credentialing or regulation, and some community colleges, universities, and freestanding institutes provide formal training. Most projects provide periodic internal sessions on topics including culturally competent care and HIPAA requirements, often required for all the organization’s staff. They also see regularly scheduled administrative and clinical supervision as opportunities for staff development.
- **Navigators as members of interdisciplinary care teams.** Navigators need to function as valued members of a clinical team in order to carry out their liaison role and maximize

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PN program value. Projects (including those of non-medical providers) that provide clinical supervision and/or maintain a close relationship with medical personnel consider this very important to project success.

- **Use of patient-centered techniques such as Motivational Interviewing** to ensure assistance that reflects each client’s unique needs and life situation.
- **Close relationships with other providers to ensure client access to needed services.** For non-medical providers, positive links with one or more clinics are a top priority. Many patients need mental health and/or substance use services, and organizations running PN programs either offer them or have agreements with providers that do. Also necessary is access to support services, from housing assistance to food banks.

Managers and navigators of the profiled programs believe that patient navigation requires special personal characteristics, knowledge, and experience. Navigators play specific, demanding roles that require clearly defined responsibilities, well designed pre-service training, and ongoing supervision, support, and in-service training, as well as strong relationships with other components of the health and human services system.

## Pitfalls and Challenges

All the profiled projects encounter and address challenges and pitfalls. Some are specific to their community, target population, or project design. The following are common across PN programs and were identified by profiled as well as non-profiled projects:

- **Transitioning clients** from PN to medical case management and/or self-management of their disease or, for high-risk HIV-negative individuals, to changed behaviors that reduce their risk of becoming HIV-positive. Navigators must develop trust with their clients, and some clients become dependent on the navigator. It can also be very hard for a navigator, after 6-18 months, to transfer responsibility for a client to someone who may provide less support. Projects address this challenge by such methods as including self-management skills development and transition preparation in client plans, and providing boundaries and transitions training for navigators. PN projects also address this challenge by having navigators support the client to become comfortable communicating with the person who will assume responsibility for their retention in care and treatment adherence.
- **Gaining support for navigators from medical personnel,** especially for non-medical providers. Navigators are most effective when they are a trusted part of the clinical team—able to share important information from patients and offer insights that can help the client enter and remain in care. However, some clinical personnel, especially physicians, see navigators as having little to contribute other than transportation assistance, likely to be unfamiliar with HIPAA and other confidentiality requirements, unaware of professional boundaries, poorly educated, and/or unable to understand HIV treatment. Successful programs find ways to overcome this initial resistance, and recommend such methods as:
  - Involving medical personnel in project planning.



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- Ensuring that medical personnel are aware of your providing solid training and support in topics like HIPAA and confidentiality of patient health information and boundaries, and preparing clients to communicate effectively with their doctors.
  - Finding a physician “champion.”
  - Providing clinical supervision to navigators.
  - Establishing a process to respond immediately to any problems between clinicians and navigators.
  - Making clinicians aware of patient improvements by sharing project performance measures that demonstrate the benefits of navigators, and giving them time to hear from patients about the valuable help navigators have provided them.
- **Obtaining project performance and client outcome data**, to determine needed refinements in the project model and to share positive outcomes with clinicians. Consider constructing an HIV care continuum treatment cascade chart for the clients and identify both successes and problem areas. Funders generally require PN projects to collect and report specific measures of success related to linkage to and retention in care, treatment adherence, and health status as part of funder quality assurance and evaluation requirements. It helps to choose appropriate measures during the design phase and determine how and by whom needed data will be collected. This can be challenging. Medical providers normally have access to viral load test results, as well as records of kept and missed appointments that indicate retention in care. Non-medical providers sometimes find it difficult to obtain such information. Even if the navigators are part of a clinical team, record their case notes in electronic medical records, and are aware of how their own clients are doing, obtaining aggregate data on all navigation clients can be difficult. Some projects have worked with medical providers or RWHAP programs to provide aggregate de-identified data on clients. Others aggregate their own data from their client records, sometimes depending on client-reported data. Christie’s Place, a non-medical provider profiled in Chapter 5, provides useful information about baseline and performance and outcome measures.
  - **Ensuring effective navigator training**, especially pre-service training, when an organization has only 1-2 navigators or is hiring one new navigator. Projects recognize the value of skill training based on interaction with a group of participants, and the time and cost savings of shared sessions. Some have access to group training from external sources—such as an institute or navigator program that offers training, state CHW courses, or courses or certificate programs at community colleges or universities. A navigation program providing Early Intervention Services in the Washington, DC, metropolitan area uses a centralized approach to training: the local public health institute hires and trains navigators and then assigns them to community-based providers and may continue to be responsible for staff development. Navigators may remain employees of the institute or be hired by the providers after the initial training has been completed.<sup>42</sup> Others provide a series of external training sessions offered by

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<sup>42</sup> See information on PN projects of Institute for Public Health Innovation at: <http://www.institutephi.org/our-work-in-action/community-health-worker-initiatives/>

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different experts, or work jointly with other navigator and CHW programs to provide joint training for a group of navigators. Many provide a combination of formal external training sessions and internal sessions tailored to their organizations. Some projects have a new navigator shadow an experienced one and incorporate opportunities for discussion and analysis of what the new navigator is seeing.

- **Identifying individuals who are newly diagnosed or out of care**, which can be a demanding and time-consuming task, often requiring personal outreach in the community. This can be accomplished by determining what subpopulations in what neighborhoods are most likely to be out of care and developing specific mechanisms to find them. Identification of these subpopulations can be done through information from their former case managers or medical providers, surveillance data, or other means. Projects sometimes redirect some navigator time to community outreach, which can mean reducing caseloads.
- **Avoiding navigator burnout**, which is detrimental to the navigators and often leads to staff turnover, which can be hard on clients and the project as a whole. Most clients who receive navigator assistance face multiple life challenges. Helping them can be extremely challenging and exhausting. Navigators need support to reduce stress and prevent burnout. Some projects offer clinical supervision to their navigators not only to discuss their challenging cases, but also to address navigator mental health and support their needs. Providing a positive work environment, where navigators are valued and receive fair salaries and benefits, also reduces burnout.
- **Finding appropriate services and referrals for high-risk HIV-negative people**, including the HIV-negative partners of HIV-positive clients. Most of the profiled projects focus on HIV-positive individuals, but also recognize the need to work with the partners of their clients and with other high-risk HIV-negative individuals, who often have many of the same needs. Obtaining needed services for HIV-positive people is often challenging. It can be even harder to help HIV-negative people, since there is no equivalent of the Ryan White HIV/AIDS Program designed for them. Projects need to develop linkages that provide their clients access to all available services as well as potentially develop new programs geared towards high-risk HIV negative people.
- **Setting and enforcing limits**, so navigators do not provide advice that should be left to clinicians and pharmacists. In the HIV field, navigators and other CHWs often assist with treatment adherence services, helping clients to understand physician and pharmacist instructions and to take their medications regularly. They also provide guidance on implementing behavioral interventions that focus on risk reduction and other aspects of living with HIV. There is concern, especially among physicians and other clinical personnel, that navigators should not provide “medical advice.” Projects need to clearly define the boundaries of navigator assistance and the kinds of advice they should and should not give. Also helpful are reminders that navigators can help their clients identify their questions and then contact their doctor or nurse to get them answered.

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## Lessons from Chapter 4

Before reviewing the detailed profile charts for each model program, take a minute to consider what information you have and what you still need to obtain from the profile charts in Chapter 5 or from other sources. A good way to use the profile charts is first to consider the following:

- The important components and approaches from your current program
- Information obtained from this chapter
- The kinds of information you hope to obtain from the models in Chapter 5

<b>Program Component</b>	<b>Components from Your Program</b>	<b>Ideas/Lessons from Chapter 4</b>	<b>Information Needed from the Chapter 5 Profiled Models</b>
Target Population(s)			
Navigator Roles and Limits			
Navigator Characteristics			
Navigator Qualifications			
Navigator Training			
Navigator Supervision and Support			
Relationships with Other Providers			
Performance and Outcomes Measures			
Other			

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## CHAPTER 5: PATIENT NAVIGATION PROGRAM PROFILES

### Objectives:

1. To provide information about effective PN programs
2. To enable users to find needed information easily
3. To provide sources of additional information about each program

Following are profiles of the five effective PN programs listed and briefly described in Chapter 4. The first two focus on cancer and diabetes, respectively. The other three are HIV-focused.

Topic	Harlem Hospital Navigation Program
<b>Organization</b>	Harlem Hospital Center
<b>Location</b>	New York City
<b>Disease Focus</b>	Breast Cancer
<b>Project Background</b>	<ul style="list-style-type: none"> <li>• Viewed as the first structured patient navigation program in the U.S.</li> <li>• Positive results contributed to increased interest in navigation programs, refinement of model, and use of model with many types of diseases</li> </ul>
<b>Target Population(s)</b>	Low-income minority patients of Harlem Hospital
<b>Time Period</b>	<ul style="list-style-type: none"> <li>• Patient navigation began in 1990; study period was for patients served from 1995-2000</li> <li>• Hospital has continued to use patient navigators in multiple departments, including volunteers and paid patient navigators for HIV-positive individuals</li> </ul>
<b>Purpose</b>	Increase breast cancer survival by increasing early-stage diagnosis and timely treatment and follow up.
<b>Client Barriers Addressed</b>	<ul style="list-style-type: none"> <li>• Financial barriers, such as no health insurance</li> <li>• Communication and information barriers including lack of accurate information</li> <li>• Medical system barriers</li> <li>• Fear, distrust, and emotional barriers</li> </ul>
<b>Service Components</b>	<p>Original program:</p> <ul style="list-style-type: none"> <li>• Provide free or low-cost mammograms.</li> <li>• Provide patient navigation to promote timely diagnosis and treatment as well as follow up, which includes “one-on-one guidance and assistance to individuals as they move through the health care continuum from prevention to end of life care.”</li> </ul>
<b>Navigator Roles</b>	<p><i>Original Project:</i></p> <ul style="list-style-type: none"> <li>• Receive a referral anytime a radiologist finds suspicion of cancer when reviewing a mammogram, a nurse practitioner determines if there is need for additional tests, or a physician schedules other clinical tests.</li> <li>• Help the patient to move through the complex system of care without delays, through a one-</li> </ul>

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Topic	Harlem Hospital Navigation Program
	<p>on-one relationship and individualized action to overcome that patient's barriers.</p> <ul style="list-style-type: none"> <li>• Provide regular feedback on the results of navigation to the clinical and administrative leaders who work with the patient navigators.</li> <li>• Function as a part of the clinical protocol.</li> </ul> <p><i>Limitations:</i></p> <ul style="list-style-type: none"> <li>• Navigators should provide services appropriate to their level of training; roles of peer navigators different from those of nurse navigators.</li> </ul> <p><i>Current Model:</i></p> <ul style="list-style-type: none"> <li>• Eliminate barriers to timely screening, diagnosis, treatment, and supportive care for each individual.</li> <li>• Act as the support hub for patients as they move through the health care system.</li> <li>• Promote smooth and timely continuity of care to the point of resolution.</li> </ul>
<b>Navigator Characteristics</b>	<ul style="list-style-type: none"> <li>• Lay people selected from the community</li> <li>• Compassionate</li> <li>• Intelligent</li> <li>• Great communication skills</li> <li>• Cultural sensitivity</li> </ul>
<b>Navigator Requirements</b>	<ul style="list-style-type: none"> <li>• Current model assumes that patient navigators can be “trained lay navigators” or “professionals such as nurses and social workers,” but should be assigned functions appropriate to their level of training and experience.</li> </ul>
<b>Training</b>	<ul style="list-style-type: none"> <li>• Lay navigators trained on the job to ensure specific skills related to each role.</li> <li>• Training for related peer CHW programs at Harlem Hospital, including HIV-focused services, quite extensive, involving a variety of training modules.<sup>43</sup></li> <li>• Freeman Institute provides an intensive 2-day in-person or online seminar that includes 10 modules; face-to-face seminar uses patient interaction and case studies; online sessions include vignettes, videos, and simulated learning—focus is on preparing participants to use the Freeman model.</li> </ul>
<b>Measures of Success</b>	<ul style="list-style-type: none"> <li>• Disease stage at diagnosis</li> <li>• Survival rate after 5 years</li> </ul>
<b>Baseline or Pre-Project Data</b>	<p>For 606 patients with breast cancer served from 1964-1986, 94% Black, all low income, half uninsured:</p> <ul style="list-style-type: none"> <li>• Stage 1 disease at diagnosis: 6%</li> <li>• Stage 3-4 disease at diagnosis: 49%</li> <li>• 5-year survival rate: 39%</li> </ul>
<b>Study/Project Results</b>	<p>For 324 patients with breast cancer served from 1990-1995, 70% Black, 26% Hispanic, all low income, half uninsured:</p>

<sup>43</sup> See Health & Disability Working Group, Boston University School of Public Health, *Building Blocks to Peer Success: a Toolkit for Training HIV-positive Peers*, 2009. Toolkit developed through the PEER (Peer Education and Evaluation Resource) Center, a collaboration that included PACT (Peer Advanced Competency Training Session), a partnership of Columbia University and Harlem Hospital. Project ended in 2009, but the Toolkit is still available on CD ROM from Boston University. See [http://peer.hdwg.org/training\\_toolkit](http://peer.hdwg.org/training_toolkit)

Topic	Harlem Hospital Navigation Program
	<ul style="list-style-type: none"> <li>• Stage 0-1 at diagnosis: 41%</li> <li>• Stage 3-4 at diagnosis: 21%</li> <li>• 5-year survival rate: 70%</li> </ul>
<b>Success Factors</b>	<ul style="list-style-type: none"> <li>• Screening provided regardless of ability to pay</li> <li>• Elimination of barriers to screening</li> <li>• Ability to reduce time delays between initial suspicious findings (e.g., an abnormal mammogram) and diagnosis, and between diagnosis and treatment</li> <li>• Improved outreach and (culturally sensitive) public education</li> <li>• Institutional support from clinical team and hospital for the patient navigator program</li> </ul>
<b>References/Contact</b>	<ul style="list-style-type: none"> <li>• Harold P. Freeman, MD, Harold P. Freeman Patient Navigation Institute. See <a href="http://www.hpfreemanpni.org/">http://www.hpfreemanpni.org/</a></li> <li>• Numerous articles describe the Harlem Project in the context of patient navigation history and principles, among them: Harold P. Freeman and Rian L. Rodriguez, "History and Principles of Patient Navigation." <i>Cancer</i>: Vo. 117, 20 July 2011. See <a href="http://onlinelibrary.wiley.com/doi/10.1002/cncr.26262/full">http://onlinelibrary.wiley.com/doi/10.1002/cncr.26262/full</a></li> </ul> <p>Study report: Oluwole SF, Freeman HP <i>et al.</i>, "Impact of a Cancer Screening Program on Breast Cancer Stage at Diagnosis in a Medically Underserved Urban Community." <i>Journal of the American College of Surgeons</i>: February 2003: 196 (2):180-188.</p>
<b>Observations</b>	<ul style="list-style-type: none"> <li>• The first formal patient navigation program.</li> <li>• Work of navigators was very focused and did not include some of the activities found in some current navigation/CHW/peer advocate programs – very strong and specific focus on support for diagnosis, treatment, and follow up (through treatment, survivorship, and end of life), with ongoing attention to identifying and helping to resolve barriers; navigator roles differentiated from outreach and advocacy.</li> <li>• Model, with some adjustments, remains widely respected and used; Dr. Freeman's Patient Navigation Institute trains navigators to use the model.</li> <li>• Model was developed for breast cancer, but is now recognized as useful in addressing other chronic disease "categories," including mental health, infectious disease, diabetes, and heart disease.</li> <li>• Navigator training was valued as a way to prepare people for employment as well as to meet health care needs.</li> </ul>

Topic	Holyoke Health Center (HHC) : Use of Community Health Workers in Chronic Disease Management (Proyecto Vida Saludable)
<b>Organization</b>	Holyoke Health Center (Federally Qualified Health Center and Level 3 Patient Centered Medical Home)
<b>Location</b>	Holyoke, MA
<b>Disease Focus</b>	<ul style="list-style-type: none"> <li>• Initial focus was on type 2 diabetes.</li> <li>• Later expanded to other chronic diseases.</li> <li>• Community health workers help manage many chronic diseases, among them asthma, diabetes, hypertension, cardiovascular disease, depression, and HIV.</li> </ul>
<b>Project</b>	<ul style="list-style-type: none"> <li>• Holyoke residents have the highest rate of diabetes mortality in Massachusetts.</li> </ul>

Topic	Holyoke Health Center (HHC) : Use of Community Health Workers in Chronic Disease Management (Proyecto Vida Saludable)
<b>Background</b>	<ul style="list-style-type: none"> <li>• Project began as a way to help HHC patients with diabetes to improve disease self-management (there were 1,200 but the number rose to 1,700).</li> <li>• Funding provided by the Robert Wood Johnson Foundation through its Diabetes Initiative.</li> <li>• Success of the diabetes project helped demonstrate the value of CHWs as part of a clinical team, and they are now involved in a wide range of HHC activities.</li> </ul>
<b>Target Population(s)</b>	<ul style="list-style-type: none"> <li>• HHC target population is residents of Holyoke, MA and Hampden County, in western Massachusetts; Holyoke is majority Latino.</li> <li>• Community health workers assist a wide range of patients, particularly those with a chronic disease.</li> <li>• For Diabetes Initiative: patients on the clinic's current registry with type 2 diabetes; group was 89% Latino/Puerto Rican and 100% lived at or below the poverty level; CHW focus was on patients who had not seen their primary care provider for routine care in at least 4 months.</li> </ul>
<b>Time Period</b>	<ul style="list-style-type: none"> <li>• Engagement of CHWs—known as <i>promotores</i>—began in 2003.</li> <li>• Assessment covered the period January 2003-January 2006.</li> <li>• CHWs later integrated into HHC's ongoing service model; some now called patient navigators.</li> </ul>
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• CHWs added to the Diabetes Initiative to enhance HHC's "capability to engage and support patients who were not succeeding in managing their diabetes."</li> </ul>
<b>Client Barriers Addressed</b>	<ul style="list-style-type: none"> <li>• Poverty</li> <li>• Co-morbidities such as mental illness and substance abuse</li> <li>• Lack of transportation and child care</li> <li>• Low literacy levels</li> <li>• Clinic hours that did not accommodate the needs of some patients</li> <li>• Knowledge gaps regarding use of medications</li> <li>• Family and other social issues affecting patients' ability to manage their medical care</li> <li>• Other medical problems requiring attention</li> </ul>
<b>Service Components</b>	<p><b>National model</b> as developed through the Robert Wood Johnson Foundation's Diabetes Initiative included the following components:</p> <ul style="list-style-type: none"> <li>• Individualized assessment</li> <li>• Collaborative goal setting</li> <li>• Development of key skills</li> <li>• Ongoing follow up and support</li> <li>• Community resources</li> <li>• Continuity of quality clinical care</li> </ul> <p><b>Holyoke's Diabetes Initiative</b> included a variety of program interventions:</p> <ul style="list-style-type: none"> <li>• Breakfast Club</li> <li>• Snack Club</li> <li>• Supermarket tours</li> <li>• Exercise classes</li> <li>• Bilingual diabetes education classes</li> <li>• Chronic disease self-management classes</li> <li>• Individual counseling (with a nutritionist or diabetes nurse educator)</li> </ul>

Topic	Holyoke Health Center (HHC) : Use of Community Health Workers in Chronic Disease Management (Proyecto Vida Saludable)
	<ul style="list-style-type: none"> <li>• Support from <i>promotores</i> in disease management</li> </ul>
<b>Navigator Roles</b>	<p><i>Promotores</i> (generally working 15-20 hours a week) responsible for identifying, engaging, motivating, and supporting patients with type 2 diabetes; roles included:</p> <ul style="list-style-type: none"> <li>• Phone outreach and home visits to patients who had missed appointments or disengaged from care and help them reconnect to care.</li> <li>• Assistance to such patients in obtaining care, through scheduling appointments, dealing with childcare, transportation, and insurance issues as needed.</li> <li>• Outreach to patients with poor glycemic control.</li> <li>• More intensive interventions with these patients, to identify barriers to disease management, engaged family or other community resources as necessary, and help patients set behavioral goals and solve problems around co-morbidities such as mental health and substance abuse issues, need for information about medications, and family stressors.</li> <li>• Linkage between patients and their clinical team (primary nurse, medical provider, pharmacist, and other team members), to assure that patients obtain needed information and services.</li> <li>• Based on referrals from primary care providers, follow up with patients (at the health center, by phone, or in patients' homes) to provide social and emotional support and education on various diabetes self-management topics.</li> <li>• Assistance as mentors, teachers, and advocates for patients.</li> <li>• CHWs now engaged in broader chronic disease management, but play similar roles.</li> </ul>
<b>Navigator Characteristics</b>	<ul style="list-style-type: none"> <li>• Peers: individuals with type 2 diabetes who are successfully self-managing their disease</li> <li>• Members of the Holyoke community who reflect the demographics of HHC's patients</li> </ul>
<b>Navigator Requirements/ Training</b>	<ul style="list-style-type: none"> <li>• Training covered topics like goal setting, problem solving, action planning, communication techniques, health literacy, and general knowledge about diabetes and was provided through multiple sources and curricula:</li> <li>• Three days of training by the Midwest Latino Research, Training, and Policy Center using the Diabetes Education and Empowerment Program (DEEP) curriculum</li> <li>• Four days of training in the Stanford Chronic Disease Self-Management Training Program</li> <li>• Several sessions of community health worker training through the Outreach Worker Training Institute in Worcester, MA</li> <li>• Leadership training at Enlace</li> <li>• Several hours of training with the HHC diabetes educator and nutritionist</li> </ul>
<b>Supervision and Support</b>	<ul style="list-style-type: none"> <li>• Supervision by a nurse</li> <li>• Weekly reviews of caseload and patient interventions with the supervising nurse</li> </ul>
<b>Measures of Success</b>	<ul style="list-style-type: none"> <li>• Reduction in percentage of registered patients with diabetes—patients who have been seen in the past three years—who have not been seen during the past year</li> <li>• Improvements in glycemic control among patients with diabetes—reduction in the average A1C (average blood sugar level) of all patients<sup>44</sup></li> </ul>
<b>Baseline Data</b>	<ul style="list-style-type: none"> <li>• 28.2% of registered diabetes patients had not been seen in the past year.</li> <li>• Average A1C for all diabetes patients was 8.4%, and 18.2% of patients had A1C levels</li> </ul>

<sup>44</sup> A typical target for the A1C level of a person with previously diagnosed diabetes is 7%.



Topic	Holyoke Health Center (HHC) : Use of Community Health Workers in Chronic Disease Management (Proyecto Vida Saludable)
	above 10%.
<b>Study/Project Results</b>	<p><i>Client outcomes:</i></p> <ul style="list-style-type: none"> <li>• 6.5% of registered diabetes patients had not been seen in the past year.</li> <li>• Average A1C for all diabetes patients was 7.5%, and 10.8% of patients had A1C levels above 10%.</li> </ul> <p><i>Other accomplishments:</i></p> <ul style="list-style-type: none"> <li>• Improved organizational capacity for self management support through staff and program development</li> <li>• Development of a <i>promotora</i> program to implement self management interventions</li> <li>• Development of a menu of self management program options to maximize patient access to intervention activities</li> <li>• Improved staff knowledge in relation to self management strategies and techniques</li> <li>• Increased awareness of the impact of health literacy on patients' ability to manage their disease</li> </ul>
<b>Success Factors</b>	<ul style="list-style-type: none"> <li>• Adoption of an electronic registry that can be used to identify patients with diabetes and identify those who are not managing their disease well or not receiving regular care</li> <li>• Addition of peer community health workers to the chronic care model, not just as outreach workers and educators, but as patient navigators who are an integral part of the clinical team, both to support ongoing medical care and to help patients overcome barriers to treatment plan adherence</li> <li>• Focus on Disease Self-Management (using the Stanford Model)<sup>45</sup></li> <li>• Extensive training</li> </ul>
<b>Challenges</b>	<ul style="list-style-type: none"> <li>• <i>Promotores</i> need ongoing training, support, and supervision from staff—which should be an integral part of the program design.</li> <li>• It can take time to build support for the role of peer navigators throughout the organization.</li> <li>• Sustainability of project interventions and the work of peer navigators after project funding ends can be challenging.</li> </ul>
<b>References/ Contact</b>	<ul style="list-style-type: none"> <li>• Study report on the Diabetes Initiative: Jon Liebman and Dawn Heffernan, “Quality Improvement in Diabetes Care Using Community Health Workers.” <i>Clinical Diabetes</i>, Volume 26, Number 2, 2008. See: <a href="http://clinical.diabetesjournals.org/content/26/2/75.full">http://clinical.diabetesjournals.org/content/26/2/75.full</a></li> <li>• Description of Holyoke Health Center Program in <i>The Diabetes Initiative: A National Program of the Robert Wood Johnson Foundation</i>. See: <a href="http://www.rwjf.org/content/dam/farm/reports/program_results_reports/2010/rwjf69955">http://www.rwjf.org/content/dam/farm/reports/program_results_reports/2010/rwjf69955</a></li> <li>• Holyoke Health Center website, including the description of services, at <a href="http://www.hhcinc.org/en/services/medical">http://www.hhcinc.org/en/services/medical</a> and the description of the Diabetes Initiative, at <a href="http://diabetesnpa.im.wustl.edu/programs/DIHHC.html">http://diabetesnpa.im.wustl.edu/programs/DIHHC.html</a></li> </ul>

<sup>45</sup> For a description of the Stanford Chronic Disease Self-Management Program, developed by the Stanford Patient Education Research Center, Stanford School of Medicine, along with several other disease self-management models, see “Common Models of Chronic Disease Self-Management Support: A Fact Sheet for Primary Care Partnerships, at <http://www.health.vic.gov.au/pch/downloads/factsheet08.pdf>

<b>Observations/ Advice</b>	Holyoke Health Center is an FQHC and a Patient Centered Medical Home with a predominantly Latino patient population that used peer community health workers ( <i>promotores</i> ) successfully as patient navigators (not just as outreach workers or health educators). Finding them effective, it has continued to include them in chronic disease management. Its navigators come from the community, mirror the client population’s characteristics, and receive several weeks of initial training, some designed in-house, some using well known national curricula. They also receive ongoing in-service training and clinical supervision.
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<b>Topic</b>	<b>Virginia Department of Health, SPNS Systems Linkages and Access to Care – Patient Navigation Strategy (Focus on Centra Health Implementation Site)</b>
<b>Organization(s)</b>	Grantee is the Virginia Department of Health (VDH). Patient Navigation strategy has been implemented by three contractors. The two initial pilot sites are Virginia Commonwealth University Medical Center (VCU) and Carilion Clinic. After a year of implementation, the model was expanded to Centra Health. A fourth site, Richmond City Health District, began implementation April 1, 2015, but is not a part of the demonstration project.
<b>Location(s)</b>	Richmond, Roanoke, and Lynchburg/Danville, in Central and Southwest Virginia. The Richmond area is largely urban, while the others are predominantly rural.
<b>Disease Focus</b>	HIV
<b>Project Background</b>	<ul style="list-style-type: none"> <li>• VDH received a competitive 4-year Special Projects of National Significance (SPNS) grant through the Systems Linkages and Access to Care for Populations at High Risk of HIV Infection initiative. Six sites received funding to “design, implement and evaluate innovative strategies to integrate different components of the public health system such as surveillance, counseling and testing, and treatment, to create new and effective systems of linkages and retention in care for hard-to-reach populations who have never been in care, have fallen out of care or are at-risk for falling out of care.”<sup>46</sup> They tested a variety of community linkage strategies, most involving some form of patient navigation. The University of California at San Francisco serves the Evaluation and Technical Assistance Center (ETAC) for the initiative.</li> <li>• VDH developed and tested four different strategies to improve linkage to care, retention in care, and/or viral suppression: (1) Mental Health, a standardized screening and referral process for individuals with mental health barriers to care; (2) Care Coordination, a process for linking to medication access and medical care HIV-positive people who are newly released from Virginia prisons and jails; (3) Active Referral, a process that requires Disease Intervention Specialists (DIS) to actively link patients to care, either directly to medical providers or through patient navigators; and (4) Patient Navigation, the model profiled here. It is designed to have impact across the entire Continuum of Care.</li> <li>• Soon after the SPNS project began, VDH received a 3-year grant from CDC for a Care and Prevention in the United States (CAPUS) demonstration project. While CAPUS is prevention-focused, it also uses patient navigators, focuses on linkage to care and health outcomes, and uses the HIV Continuum of Care/Treatment Cascade measures to determine outcomes.</li> <li>• To separately test each model and avoid contamination of the evaluation component, the</li> </ul>

<sup>46</sup> Description of the initiative from the SPNS website. See <http://hab.hrsa.gov/abouthab/special/systemslinkages.html>

Topic	Virginia Department of Health, SPNS Systems Linkages and Access to Care – Patient Navigation Strategy (Focus on Centra Health Implementation Site)
	<p>CAPUS and SPNS Patient Navigation models operate in different regions of the State.</p> <ul style="list-style-type: none"> <li>• This profile provides information on the navigation strategy and on the third implementation site, Centra Health, with its primary site in Lynchburg and a satellite site in Danville. One navigator works in Danville, and the project team travels there one day a week to provide medical and other services.</li> </ul>
Target Population(s)	<ul style="list-style-type: none"> <li>• <b>Newly Diagnosed:</b> Individuals who have been diagnosed with HIV within the last 90 days</li> <li>• <b>Lost to Care /Re-engaged:</b> Individuals who have not attended a medical appointment in 6 months or longer, or who have never been engaged in HIV care</li> <li>• <b>“At-Risk” of Falling out of Care:</b> Individuals who attend medical appointments sporadically and/or have other barriers that may affect their ability to stay in HIV care</li> </ul> <p>The three sites serve a high proportion of PLWH from racial/ethnic minorities, particularly African Americans. VCU and Centra were formerly Minority AIDS Initiative (MAI) sites. Centra operated a program using navigators to link first women of color and then both women and men to RWHAP services and help them stay in care. An increasing proportion of Centra clients are young MSM, both African American and White.</p>
Time Period	<ul style="list-style-type: none"> <li>• The first project year was spent in planning and protocol development. Implementation began in September 2012 at the Richmond and Roanoke sites and in September 2013 at the Lynchburg expansion site. The demonstration period was scheduled to end in August 2015, but a no-cost extension was expected to support continued implementation through March 2016.</li> <li>• VDH expects to continue supporting patient navigation services after that time, through a mixture of CDC prevention and Ryan White Part B and MAI funds. It will use the SPNS strategy or a hybrid with the CAPUS model.</li> </ul>
Purpose/Goals	<p>The main goal of the Patient Navigation strategy is to increase linkage and retention in medical care for individuals living with HIV. Additional goals are to:</p> <ul style="list-style-type: none"> <li>• Address barriers to care</li> <li>• Ensure medication access and access to medical care</li> <li>• Ensure access to any needed support services</li> <li>• Transition clients to medical case management or other necessary community services</li> </ul>
Barriers Addressed	<ul style="list-style-type: none"> <li>• Navigators work with clients to identify and address barriers beginning at Intake. Project forms identify many possible barriers, but the navigators do not ask clients whether they face a particular barrier. Instead they use Motivational Interviewing that allows clients to identify barriers they feel are important.</li> <li>• The strategy Barriers Checklist and other project documents together list the following potential barriers to linkage and/or retention in care: <ul style="list-style-type: none"> <li>– Transportation/logistics (includes scheduling issues, such as the need to work during clinic hours)</li> <li>– Employment/financial</li> <li>– Insurance/benefits (includes co-pays and other cost sharing)</li> <li>– Child care</li> <li>– Unstable housing</li> <li>– Mental health</li> <li>– Substance abuse</li> </ul> </li> </ul>

Topic	Virginia Department of Health, SPNS Systems Linkages and Access to Care – Patient Navigation Strategy (Focus on Centra Health Implementation Site)
	<ul style="list-style-type: none"> <li>– Stigma/social barriers</li> <li>– Clinical/medical (includes issues with current medical provider, distrust of the medical system)</li> <li>– Medication adherence</li> <li>– Legal</li> <li>– Food/nutrition</li> <li>– Perceived “red tape and bureaucratic hassles”</li> </ul>
Service Components	<p>The Patient Navigation strategy calls for navigators to be involved with individual clients for up to 12 months:</p> <ul style="list-style-type: none"> <li>• <b>Linkage to care</b>, an intensive period of up to three months that includes the initial referral to the navigator, verification of the first medical appointment, intake, the first medical visit, and initial assessment of barriers to care and treatment plan development. Key timing: <ul style="list-style-type: none"> <li>– Within 72 hours, navigator indicates s/he has received the referral.</li> <li>– Within 72 hours of referral, navigator makes first contact with the client, and verifies or schedules the first medical appointment; if first attempt is unsuccessful, second attempt is made within five days and third attempt within seven days.</li> <li>– Within two weeks after referral, navigator completes Intake with client; includes client assessment and linkage to care plan.</li> <li>– Within two weeks after first contact where possible, or definitely within 30 days, client has his/her first medical visit.</li> <li>– After first visit, navigator works with client to further assess and begin to address barriers to care, provide health education, link client to other needed services, and provide other assistance to ensure full linkage to care.</li> </ul> </li> <li>• <b>Retention services</b>, usually Months 4-6, but can begin as early as Month 2 and includes: <ul style="list-style-type: none"> <li>– Continued support to the client through electronic and face-to-face contact, to help the client continue in medical care, obtain other needed services, and gain skills for transition to a case manager and/or disease self-management.</li> <li>– Periodic reassessment of barriers and progress towards resolving them, as well as development of a retention in care plan and later a transition plan.</li> </ul> </li> <li>• <b>Services to ensure full engagement in care</b>, which usually begin Month 6 or 7 and may continue as long as Month 12; includes: <ul style="list-style-type: none"> <li>– Updating of the client assessment and preparation for transition after six months (consistent with timing for eligibility re-certification for RWHAP services).</li> <li>– Continued support to the client, usually at a reduced intensity, to address remaining barriers and ensure that the client is receiving needed medical-related and support services, is fully engaged in care, and is treatment adherent.</li> <li>– Skill development and other support to prepare the client for the transition to case management and/or disease self-management.</li> <li>– Implementation of the transition and completion of client discharge from navigation</li> </ul> </li> </ul>

<p><b>Navigator Roles</b></p>	<p>Patient navigators are expected to “support client linkage and retention in HIV care for up to 12 months.” Responsibilities include:</p> <ol style="list-style-type: none"> <li>1. Facilitate entry into medical care for targeted HIV-positive individuals.</li> <li>2. Provide client-centered counseling to assess and address client barriers to linkage and retention in HIV medical care.</li> <li>3. Facilitate client linkage to medical care and needed support services and provide necessary follow up to support client retention in care.</li> <li>4. Provide client-centered education related to HIV disease, medical care, medications, and risk-reduction.</li> <li>5. Use client-centered Motivational Interviewing techniques to engage and empower the client toward self-management; this includes skills training on how to interact with medical providers.</li> <li>6. Transition clients from navigation to community services (such as case management) or self- management of their HIV medical care.</li> <li>7. Build relationships and communicate with providers and community agencies to accelerate and enhance client linkage and retention in care.</li> <li>8. Facilitate the early identification of individuals with HIV/AIDS (EIIHA) by providing referrals to HIV testing for contacts and partners of clients and distributing in-home HIV test kits in circumstances where referrals to test sites are not feasible.</li> </ol> <ul style="list-style-type: none"> <li>• Some navigators are trained and called upon to help clients obtain insurance through the ACA marketplace.</li> <li>• Navigators often receive referrals from DIS or other agencies. In addition, they do active recruitment. This may involve community outreach to find out of care individuals and/or referrals of HIV-positive people from sources such as: local health departments, agencies that conduct HIV testing and referral services, medical providers, and case managers.</li> <li>• Some navigators work with clients that are served by private medical providers rather than clinics. These clinicians depend on the navigators to make referrals for other needed medical-related and support services and to address client barriers to care.</li> <li>• Navigators are not told there are any roles they must not play. They receive a lot of flexibility to do their work, and have a variety of individual skill sets beyond those essential to their jobs.</li> </ul>
<p><b>Supervision and Support</b></p>	<ul style="list-style-type: none"> <li>• Each implementation site has a different supervisory structure for its navigators; they include: <ul style="list-style-type: none"> <li>– Medical Director—primary supervisor with technical supervision; project administrator—administrative supervision</li> <li>– Ryan White HIV/AIDS Program Director</li> <li>– Supervising nurse</li> </ul> </li> <li>• At some sites, the Medical Director is closely engaged. At some sites, the navigators meet weekly with the Medical Director.</li> <li>• VDH holds monthly telephone calls with SPNS-supported patient navigators from all three sites, and now also includes navigators working in the Richmond City Health District.</li> <li>• Navigators from all sites now meet approximately three times a year for training, information sharing, and problem solving.</li> </ul>
<p><b>Navigator Characteristics</b></p>	<p>Navigators need to care about assisting clients, and be creative and determined in overcoming obstacles and solving problems, effective at showing empathy and developing trust with clients, and able to define and maintain boundaries. They need to be focused on helping clients overcome barriers and learn disease self-management skills and committed to preventing</p>

	<p>dependence on them. They also need to have knowledge of community resources and services.</p> <ul style="list-style-type: none"> <li>• VDH also identifies the following as valuable navigator characteristics, as identified in the <i>Patient Navigation Toolkit</i>:<sup>47</sup> <ul style="list-style-type: none"> <li>– Compassion</li> <li>– Intelligence</li> <li>– Great communication skills</li> <li>– Cultural sensitivity</li> <li>– Ingenuity</li> </ul> </li> </ul>
<p><b>Navigator Qualifications/ Requirements/ Preferences</b></p>	<ul style="list-style-type: none"> <li>• Each contractor develops its own specific job description and requirements, and hires its own patient navigators. VDH has provided a sample job description that suggests the following minimum qualifications: <ul style="list-style-type: none"> <li>– Familiarity with client-centered approaches to service delivery</li> <li>– Strong skills in networking with HIV services providers, the community and high-risk populations</li> <li>– Strong interviewing and oral communication skills</li> <li>– Ability to provide culturally competent and sensitive health and risk reduction educational messages</li> <li>– Ability to work in a team setting</li> <li>– Strong time management skills</li> <li>– Knowledge of community resources and the ability to develop new linkages in the community</li> <li>– Familiarity of health care delivery/services in particular service area</li> </ul> </li> <li>• Education or related experience is stated a “desired” qualification: “Bachelor’s Degree in health-related field <b>or</b> a minimum of three years’ experience working within a health care delivery system, substance abuse, mental health, with incarcerated individuals, or in HIV service provision.”</li> </ul>
<p><b>Navigator Training</b></p>	<ul style="list-style-type: none"> <li>• Training of the first group of navigators was done under contract by the Pennsylvania/Mid-Atlantic AIDS Education and Training Center’s Northern Virginia performance site, the Inova Juniper Program of Inova Health Systems. Training was provided through quarterly in-person sessions, monthly webinars, and technical assistance sessions. Topics addressed the following core competencies: <ol style="list-style-type: none"> <li>1. In person training: <ul style="list-style-type: none"> <li>– The Role and Practices of the SPNS Patient Navigator</li> <li>– HIV Facts: HIV Disease Basics: Medical, Life Cycle, Treatment and Adherence</li> <li>– Introduction of Critical Concepts: Motivational Interviewing, Facilitating the Client-Provider Relationships, Exploring Barriers to Care</li> <li>– Motivational Interviewing (MI) - Intensive (2 days)</li> <li>– HIV Prevention Counseling: The Fundamentals and Home Testing Hands-On</li> </ul> </li> <li>2. By webinar: <ul style="list-style-type: none"> <li>– Field Safety Overview</li> <li>– Home Testing Kits Protocol/Guidelines and Guidance: The Basic Lab Results, Rapid Methodologies, Procedures for Referring, Protocol Follow-Up</li> </ul> </li> </ol> </li> </ul>

<sup>47</sup> The Toolkit was developed through sponsorship of the Chicago Land Area Affiliates of Susan G. Komen for the Cure and the National Patient Navigation Leadership Summit Committee, following the March 2010 Summit. The disease focus is cancer, but the roles of navigators are similar to HIV navigators. See <http://patientnavigationtoolkit.com/>

	<ul style="list-style-type: none"> <li>– Cultural Competency Overview</li> <li>– Linkage to Care and Active Referrals</li> <li>– Disclosure and Stigma</li> <li>– Patient Navigation: Client Perspectives</li> <li>– Self-Care and Managing Stress Related to the Patient Navigator Role</li> <li>– Sexually Transmitted Infections (STIs)</li> <li>– Recognizing Mental Health, Substance Abuse, Psychosocial Issues</li> <li>– Dealing with Difficult Clients</li> </ul> <ul style="list-style-type: none"> <li>• The Institute for Drug and Alcohol Studies (IDAS) at the Virginia Commonwealth University in Richmond provided the two days of Motivational Interviewing training.</li> <li>• Future navigators will also receive training on the use of the project protocol.</li> <li>• Contractors also have their own “on-boarding” and employee training. For example, Centra requires mandatory continuing education each year that includes such topics as HIPAA, blood pathogens, and employee and patient safety.</li> </ul>
<b>Measures of Success</b>	<ul style="list-style-type: none"> <li>• The major outcome measures for the SPNS clients are based on the Continuum of Care/Treatment Cascade and include: <ul style="list-style-type: none"> <li>– <b>Linkage to care:</b> Linked within 90 days if newly diagnosed</li> <li>– <b>Retention in care:</b> Over 12 months, two or more care markers at least three months apart; care markers include CD4 count, viral load, prescription for anti-retrovirals, or a medical visit.</li> <li>– <b>Viral suppression:</b> At last viral load test, <math>\leq 200</math> copies/mL</li> </ul> </li> <li>• For the SPNS initiative as a whole, the national evaluation center is also addressing this question: “What are the structural, policy, provider, and patient characteristics that facilitate or hinder implementation of system linkage interventions?”</li> <li>• The ETAC is also looking at important practical factors such as the appropriate minimum “dosage” (level of encounters/services provided by the navigator) required for success with each of the three types of clients.</li> </ul>
<b>Baseline Data</b>	<ul style="list-style-type: none"> <li>• Baseline data are historical data on Ryan White clients receiving services in the regions where the patient navigation sites are located. VDH is able to provide data separately for each of the three types of clients (newly diagnosed, out of care, at risk of falling out of care).</li> <li>• The project evaluation will compare success measures data for clients with navigators with data from the same types of clients (newly diagnosed, out of care, and in danger of falling out of care) in the same regions who did not receive patient navigation services.</li> </ul>
<b>Study/Project Results</b>	<ul style="list-style-type: none"> <li>• Outcomes data are not yet available. The sites and the ETAC have one year after the end of the demonstration period (August 2015) to complete the evaluation. However, the project is seeing improvement in client outcomes/success measures from year to year.</li> <li>• Some qualitative data from clients have been collected through interviews conducted at the VCU site. Results indicate that clients have been retained in care and consider the navigation services very helpful.</li> <li>• Some preliminary cross-site observations from the ETAC include the following: <ul style="list-style-type: none"> <li>– “Overall, patients are responding well to the interventions.</li> <li>– Interventionists are spending more time with patients than anyone else in the clinic.</li> <li>– ‘Fieldwork’ is a common feature and a necessary activity to reach out of care patients.</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>– Newly diagnosed patients have different (lesser) needs than those who are out of care.</li> <li>– Goals to support newly diagnosed patients are clear: support to 1) cope with diagnosis and 2) link and remain in care.”<sup>48</sup></li> <li>• As part of the evaluation, the project expects to produce practical information helpful in designing future navigation projects, such as the minimum “dosage” (e.g., number/frequency of encounters) needed for reaching desired outcomes, and whether the location of the encounter makes a difference.<sup>49</sup></li> </ul>
<b>Success Factors</b>	<p>Staff identified the following factors as contributing to project success:</p> <ul style="list-style-type: none"> <li>• <b>Commitment to the project:</b> There is “a lot of buy-in” from the navigators and from the contractors/service providers, who helped with the planning. They believe in what they are doing. Navigators were described as highly motivated as well as highly skilled. At Centra in Lynchburg, collaboration and commitment are facilitated because the whole ten-person HIV team has offices together and a secure communications system that allows for emailing some client information. Team members work together to welcome new clients, who are introduced by the navigator.</li> <li>• <b>Motivational Interviewing and Fidelity Monitoring:</b> An important success factor is client-centered Motivational Interviewing approach, which lets the client lead the discussion. It was noted that clinicians have an agenda to follow during medical visits, while the navigator’s focus is on the patient’s agenda. To ensure that navigators are implementing Motivational Interviewing as planned, VDH has contracted with VCU’s Institute for Drug and Alcohol Studies for Fidelity Monitoring. The Institute receives and assesses taped sessions provided by each navigator, then provides feedback directly to the navigator, not to the supervisor. If the navigator is not using Motivational Interviewing as specified in the training, the navigator receives additional training and support.</li> <li>• <b>Use of home test kits:</b> Being able to provide home test kits for use by partners or contacts who cannot be reached at testing sites is efficient and practical for navigators.</li> <li>• <b>Cultural competence:</b> All navigators need to be culturally sensitive and to understand how culture affects client needs and use of services. This is a part of their training. The PLWH served are majority African American, and five of the six current navigators are African American.</li> <li>• <b>Navigator as part of an interdisciplinary team.</b> Within the contracted provider, navigators in this program strategy are treated as part of a service team including clinical staff. They generally meet regularly with the clinical team and have access to electronic health records (EHRs) for information such as viral load and other laboratory test results. Navigators at Centra enter their case notes directly into client EHRs. Project staff consider a close link between the navigator and medical staff and services very beneficial.</li> </ul>
<b>Challenges</b>	<ul style="list-style-type: none"> <li>• <b>Building inter-organizational teams:</b> It can be challenging to build fully collaborating teams when some team members work for partner organizations rather than all of them working for the organization that runs the navigation program. For example, when case managers work for a different organization, there may be less initial willingness to share information with navigators and to encourage their involvement with case management</li> </ul>

<sup>48</sup> Ryan White Part B Program Technical Assistance Webinar on Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative, March 15, 2015. Archived webcast and PowerPoint available at <https://careacttarget.org/library/systems-linkages-and-access-care-populations-high-risk-hiv-infection-0>

<sup>49</sup> For more information about VDH’s documentation and evaluation efforts, contact Kathryn Gilmore, Data Manager, Systems Linkages and Access to Care Initiative, Division of Disease Prevention, Virginia Department of Health at [Kathryn.Gilmore@vdh.virginia.gov](mailto:Kathryn.Gilmore@vdh.virginia.gov). For more information about the national evaluation of this SPNS initiative, follow the website managed by the ETAC, the University of California, San Francisco, at <http://hivlinkage.ucsf.edu/>



	<p>clients. Over time, navigators can usually demonstrate the value of the support and assistance they provide, but full cooperation may take more time to establish.</p> <ul style="list-style-type: none"> <li>● <b>Rural challenges:</b> Two of the three implementation sites are in rural areas, where transportation, child care, and communications can be challenging. <ul style="list-style-type: none"> <li>– <i>Transportation:</i> Clients often need transportation assistance to get to appointments, and public transportation is very limited. Navigators often have to travel a considerable distance to meet with clients. The Centra site owns a van that navigators use in transporting clients, and sometimes uses a vehicle owned by the health system or even rents a car. Sometimes appointments must be rescheduled if the client does not have child care, it is not available at the service site, and the vehicle is not equipped with an appropriate child seat. Centra's van is aging, and it would be difficult to meet transportation needs without it. However, projects do not want their navigators to be viewed as a transportation service.</li> <li>– <i>Communications:</i> It is often hard to get information to the people who need it, especially since no identifying or confidential patient information can be shared in a text or voicemail message. Navigators at Centra have learned to text patients, since clients may have limited telephone minutes.</li> <li>– <i>Coordination:</i> Coordination among team members is complicated by distances. For example, the navigator may need to travel a long distance with little notice to pick up a new client just released from jail and help in arranging and picking up needed medications.</li> </ul> </li> <li>● <b>Client transition from the patient navigation:</b> Helping clients make the transition from the navigator to a case manager and/or disease self-management can be very challenging. Often clients trust the navigator and are afraid they won't be able to get needed services and support without the navigator. In rural areas, they may be particularly concerned about how they will get to their appointments. It can also be hard for the navigator to "let go," passing responsibility for the client to a case manager. Addressing this challenge requires that the navigators receive appropriate boundaries and transition training. In addition, a transition plan needs to be developed and the navigator and client need to begin preparing for the transition early in the navigation process.</li> <li>● Record keeping for a pilot project is extensive, and health system EHRs are not compatible with databases used by HIV prevention and RWHAP programs. Forms are also different. This can mean entering client data into two different systems or onto two different forms.</li> </ul>
<p><b>References and Contacts</b></p>	<ul style="list-style-type: none"> <li>● Information for this profile was obtained through: <ul style="list-style-type: none"> <li>– Discussions with three VDH representatives and one representative of a patient navigation strategy contractor, Centra Health, who also obtained input from Centra's navigators.</li> <li>– The March 18, 2015 SPNS webinar on the Initiative.</li> <li>– The review of project materials, especially the draft VDH State Linkage to Care Manual and the draft Virginia SPNS Systems Linkages Initiative Patient Protocol.</li> </ul> </li> <li>● Final versions of the project Manual and Patient Protocol were expected to be available from VDH or SPNS around September 2015.</li> <li>● For more information about the VDH project, contact Safere Diawara at <a href="mailto:Safere.Diawara@vdh.virginia.gov">Safere.Diawara@vdh.virginia.gov</a> or at 804-864-8021.</li> </ul>
<p><b>Observations and Advice</b></p>	<ul style="list-style-type: none"> <li>● VDH is committed to the use of patient navigation throughout the Commonwealth, and "to doing it right," by looking at evaluation data (e.g., improvement in linkage, retention, and viral suppression) and exploring factors that influence success. For example: <ul style="list-style-type: none"> <li>– Structural factors, such as where the navigator is placed within the organization and who provides supervision</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>– Client race/ethnicity, gender, and other characteristics</li> <li>– Differences in encounter frequency, length, location, method, and services provided, including the minimum “dosage” (e.g., number, frequency) of navigator encounters needed to attain success (which can also help in deciding an appropriate caseload for a navigator)</li> <li>• The initial project protocol focused on newly diagnosed individuals, but additions are being made to encourage and guide outreach and recruitment of PLWH who are out of care or in danger of falling out of care—recognized as important tasks that can require a considerable investment of navigator time.</li> <li>• The project identifies a variety of databases and sources for documentation and evaluation, among them Ryan White, ADAP, eHARS (surveillance), Medical Monitoring Project (MMP), and the Virginia all payer claims database (for clients with private insurance, Medicaid and Medicare). In addition, because this is a demonstration project numerous forms to record plans, activities, and case notes are used. The forms and database use may be helpful to organizations developing their first patient navigation project and are documented in the project manual and protocol.</li> <li>• VDH recommends Fidelity Monitoring (sometimes called “design evaluation”) as a way to ensure that core components of the strategy such as Motivational Interviewing are being implemented as planned.</li> <li>• As the SPNS project ETAC has noted, patient navigation has emerged as a key strategy for HIV linkage to and retention in care, but there are large variations in patient navigation programs. Organizations need to determine the core components and approaches that fit their own structures and the needs of their target populations.</li> </ul>
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<b>Topic</b>	<b>Christie’s Place: CHANGE for Women (C4W) (Coordinated HIV/AIDS Navigation, Growth and Empowerment)</b>
<b>Organization</b>	Christie’s Place
<b>Location(s)</b>	San Diego, CA – Serves San Diego County
<b>Disease Focus</b>	HIV
<b>Background on Use of CHWs/ navigators</b>	<ul style="list-style-type: none"> <li>• Since it was founded in 1996, Christie’s Place has used a peer-support model, which has been continually refined and strengthened to benefit both clients and peers. The organization provides comprehensive HIV education, screening, support, and advocacy. Peer community health workers (called Peer Advocates) have provided health education and outreach, information and referral, as well as enrolled into and provided non-medical case management services, facilitated support groups, and done advocacy.</li> <li>• • The 2006 Ryan White Act reauthorization required the use of at least 75% of service dollars for core medical-related services. In 2007, Christie’s Place expanded its peer services into a clinical services model, with peers serving as family caseworkers.</li> <li>• Christie’s Place has worked to increase program effectiveness with women who have never been in care or have fallen out of care. In 2010, the unmet need estimate<sup>50</sup> for San Diego County found that 69% of women who knew their HIV status had been out of care—had</li> </ul>

<sup>50</sup> The unmet need estimate is defined by HRSA’s HIV/AIDS Bureau as the percent of HIV-positive individuals living in a geographic area who have not received HIV-related primary medical care for at least 12 months.

Topic	<p style="text-align: center;"><b>Christie’s Place: CHANGE for Women (C4W)</b>  <b>(Coordinated HIV/AIDS Navigation, Growth and Empowerment)</b></p>
	<p>received no HIV-related medical care—for 12 months or more. Christie’s Place engaged with the University of California San Diego, two FQHCs, and other agencies to address this unacceptable situation through strategies such as peer/patient navigation and trauma-informed service delivery, as well as system-wide network of care model. In four years, the unmet need rate had decreased by 14 percentage points, to 55%. Efforts to further reduce the level of unmet need are ongoing.</p> <ul style="list-style-type: none"> <li>• In 2010, Christie’s Place began to use the Bridge and Promotora models, engaging peers as patient navigators to find women who are not in care, linking them to medical care and other services, and helping retain them in care. Peers received more intensive training and support, and some were outstationed with clinical partners, becoming part of care planning groups and interdisciplinary teams.</li> <li>• By 2010, the peer program was serving over 1,100 HIV-positive individuals and their affected family members annually.</li> <li>• Since 2010, Christie’s Place has operated CHANGE for Women (C4W), a peer navigation program funded in part by AIDS United Access to Care Initiative. Social Innovation Fund investments began in 2011. Christie’s Place is exploring ways to continue these services, including discussions with the RWHAP Part A grantee.</li> <li>• Christie’s Place has RWHAP Part A funding to deliver Early Intervention Services,<sup>51</sup> Medical Case Management, and Outreach for women, children, and families; peer navigation is interwoven into this integrated model.</li> <li>• Christie’s Place is currently involved in the National Institute of Mental Health-funded study <i>Implementation of an Evidence Based PTSD Treatment in Public Sector Settings</i>. It is the only community-based organization involved in this multi-site study and the only site focused on women living with HIV and their affected family members. The aim of this study is to assess the effectiveness of the evidence-based intervention Skills Training in Affective and Interpersonal Regulation (STAIR) Narrative Therapy Treatment for individuals living with PTSD resulting from interpersonal violence. Christie’s Place is working on integrating components of this evidence-based model into peer navigation services.</li> <li>• Increased peer training, clinical and administrative supervision, and increased use of evaluation have contributed to better peer retention, more continuity in care, and more effective support for clients.</li> </ul>
<p><b>Target Population(s)</b></p>	<ul style="list-style-type: none"> <li>• HIV-positive women along with their children and families.</li> <li>• C4W targets HIV-positive women of all ages who face barriers to accessing and remaining in HIV-related medical care, including newly diagnosed women who have never been in care and women who are out of care.</li> <li>• Most clients are women of color.</li> </ul>
<p><b>Time Period</b></p>	<ul style="list-style-type: none"> <li>• Use of patient navigators and other peer staff (caseworkers) is ongoing.</li> <li>• Social Innovation Fund resources for the peer navigation program were first received through AIDS United in 2011, and that funding ends in February 2016.</li> </ul>
<p><b>Purpose</b></p>	<ul style="list-style-type: none"> <li>• Christie’s Place was established to empower women, children, and families whose lives have been impacted by HIV to take charge of their health and wellness. It provides gender-responsive and trauma-informed services that support access to healthcare for women,</li> </ul>

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<sup>51</sup> See Chapter 2, page 14, for a description of Early Intervention Services (EIS) as funded through the Ryan White HIV/AIDS Program.

Topic	<b>Christie’s Place: CHANGE for Women (C4W)</b> <b>(Coordinated HIV/AIDS Navigation, Growth and Empowerment)</b>
	<p>children, and families impacted by HIV.</p> <ul style="list-style-type: none"> <li>• The purpose of C4W is to improve underserved women’s access to and retention in HIV care.</li> </ul>
<b>Client Barriers</b>	<ul style="list-style-type: none"> <li>• Economic/financial status (low income)</li> <li>• Unfilled basic needs (child care, transportation, food)</li> <li>• Tendency to place their own needs last—leading to delayed testing or entry into care</li> <li>• Difficulty in accepting their HIV diagnosis</li> <li>• Intimate partner/domestic violence and other trauma, past and current</li> <li>• Language barrier</li> <li>• Immigration status—fear of taking public transportation or going to a clinic because they might be detained and deported</li> <li>• Behavioral health issues —mental health and substance abuse</li> <li>• Concerns about confidentiality and mistrust of the “system”</li> <li>• Societal conditions—e.g., discrimination, economic downturns, isolation of some communities</li> <li>• Cultural views around health and wellness/psychosocial issues</li> </ul>
<b>Service Components</b>	<ul style="list-style-type: none"> <li>• Peer navigation services involve a variety of strategies and components.</li> <li>• Integrated clinical and social services, a one-stop shop offering case management, mental health services, substance abuse counseling and “basic needs” assistance, including transportation, child care, food, clothing, etc.</li> <li>• C4W has placed peers in three clinics in the San Diego area and used a mobile/home-based model in which HIV-positive peers meet with clients at clinic sites and in their homes and communities to more effectively address their barriers to care. The two-part model includes: <ul style="list-style-type: none"> <li>– <i>A2C (Access to Care):</i> Network of Care Model, a system-wide collaborative care approach to address access and linkage to care by identifying women who are out of care and supporting them back into the local HIV care continuum.</li> <li>– <i>RiC (Retention in Care):</i> Use of interventions that strengthen RiC and ART adherence, including trauma-informed services (which is done agency-wide), integrated treatment teams to assess, identify, and treat specific RiC barriers, and tailored services to address specific barriers.</li> </ul> </li> <li>• Services are ongoing.</li> </ul>
<b>Relationships with Partner Organizations</b>	<ul style="list-style-type: none"> <li>• Developing trust and becoming part of a clinical team can be complicated, especially for CBOs like Christie’s Place that are not medical providers.</li> <li>• Christie’s Place is a <i>clinical</i> provider (medical case management, mental health services, and substance abuse services) with a Clinical Director (Licensed Marriage and Family Therapist) who is considered a peer of medical providers. This increases their confidence in the training, supervision, and professionalism of the navigators. Knowing that navigators have received HIPAA and other substantive training also adds credibility.</li> <li>• Christie’s Place looks for “champions” within medical providers—physicians or other clinicians who understand the value of navigators and help them become integrated into interdisciplinary teams.</li> <li>• Initially, some physicians, nurses, or case managers may see the navigators as primarily transportation providers or babysitters, but over time clinicians see positive changes in health outcomes, patients talk about how their navigators have helped them, missed appointments decrease, patients come into appointments better prepared to share concerns and ask questions—and the primary care providers begin to view navigators as valuable members of the treatment team.</li> </ul>

Topic	<b>Christie’s Place: CHANGE for Women (C4W)</b> <b>(Coordinated HIV/AIDS Navigation, Growth and Empowerment)</b>
	<ul style="list-style-type: none"> <li>Client “ownership” issues can arise with partner organizations other than medical providers. Sometimes there may be a fear that Christie’s Place will “steal” their clients. It takes time and relationship building to develop mutual support and cross-referrals, but as the navigators become known and partner staff see positive results, relations become mutually supportive.</li> </ul>
<b>Navigator Roles</b>	<ul style="list-style-type: none"> <li>Serve as a member of a multidisciplinary team, actively promote greater understanding of clients’ point of view and preferences, and advocate on behalf of clients when appropriate.</li> <li>Do outreach at designated partner agencies and community locations to identify HIV-infected women who are newly diagnosed, have fallen out of care, or are in danger of falling out of care.</li> <li>Re-engage women who have fallen out of care through activities such as telephone follow up with clients who do not make their primary care appointments, follow up with primary care providers, scheduling of client appointments (or help to clients in making their own appointments), and reminder calls. Navigators sometimes drive clients to their appointments, attend client appointments, and help with interpretation for clients with limited English.</li> <li>Conduct informal assessments of the client’s need for primary care and treatment, support services, early intervention/diagnosis information, and peer-based counseling.</li> <li>Provide assistance in accessing appropriate services and resources.</li> <li>Facilitate referrals to core services and linkages to support services as needed.</li> <li>Carry out the <i>My Chart</i> strategy: Increase women’s access to their own health records through use of the online electronic health records (EHRs) available to patients of the University of California, San Diego women’s clinic. Peer navigators are trained and they train their clients to access and review their EHRs. Peers help clients to discuss their questions and concerns, email their doctors, or prepare to ask appropriate questions during their next appointment.</li> <li>Prepare and distribute women-specific, culturally and linguistically appropriate materials related to the needs of clients.</li> <li>Promote/interpret peer navigator services to the community.</li> <li>Roles not played: Navigators are not pharmacists and do not provide guidance on medications.</li> </ul>
<b>Navigator Characteristics</b>	<ul style="list-style-type: none"> <li>HIV-positive and “out” about their status</li> <li>Reflective of the community and Christie’s Place clients—and often have had a lot of the same issues as our clients</li> <li>Deep commitment to helping women succeed in overcoming barriers, entering care, and staying in care</li> </ul>
<b>Navigator Qualifications/ Requirements</b>	<ul style="list-style-type: none"> <li>Other work experience, including with social services, is required. Other peer CHWs need not have as much training or experience and can be mentored and coached, but navigators are expected to be able to work independently once they have completed their pre-service training.</li> <li>Knowledge of HIV and related social issues.</li> <li>It is necessary to have a valid driver’s license and a vehicle to use on the job.</li> <li>Knowledge of HIV infection and related social/emotional issues.</li> <li>Ability to demonstrate competency in working with culturally diverse, low/no income clients, and special populations.</li> <li>Office skills including proficiency in Microsoft Word and Access, and professional phone etiquette.</li> </ul>

Topic	<p align="center"><b>Christie’s Place: CHANGE for Women (C4W)</b>  <b>(Coordinated HIV/AIDS Navigation, Growth and Empowerment)</b></p>
	<ul style="list-style-type: none"> <li>• Strong communication and interpersonal skills including diplomacy, tact, and flexibility.</li> <li>• Ability to use training and remain calm during potential emergencies or crises.</li> <li>• Well organized and detail oriented.</li> <li>• Ability to work effectively with others, including clients, co-workers, and service providers.</li> <li>• Christie’s Place hires peers as navigators. While it is important that its navigators are HIV-positive, there are many ways to define a “peer.” For example, past substance abuse can be a valuable source of life experience that enables a navigator to understand and assist her clients. Similarly, a criminal history can help navigators understand the issues facing formerly incarcerated HIV-positive women, although some crimes will exclude applicants. These include sex offenses, murder and other violent crimes, and Medi-Cal fraud.</li> <li>• No educational requirements.</li> </ul>
<p><b>Navigator Training</b></p>	<ul style="list-style-type: none"> <li>• <b>Front-end training:</b> Navigators usually provide no client services for the first 2-3 months. <ul style="list-style-type: none"> <li>– Some training done through the LOTUS Project</li> <li>– Motivational Interviewing training</li> <li>– Specific training (as well as personal experience) on substance abuse and trauma recovery</li> <li>– Specific training in navigation tasks</li> <li>– Topics like safety when working out in the “field”</li> </ul> </li> <li>• <b>Shadowing:</b> New navigator goes out with an experienced navigator.</li> <li>• <b>In-service training:</b> Eight hours a month, provided the first Monday of every month, when Christie’s Place is shut down (no clients)—varied topics, some clinical, such as working with refugees, serving the formerly incarcerated; cultural competence, trauma-responsive care.</li> <li>• Christie’s Place has benefited from participation in the LOTUS Project, which works with HIV-positive women to develop and implement Peer Advocacy Education and Training around the country. It supports a women-centered approach to address the disproportionate impact of HIV among women by: <ul style="list-style-type: none"> <li>– Providing peer advocate training to HIV-positive women who can provide emotional and practical support to other HIV-positive women.</li> <li>– Building partnerships with other women-centered organizations like Christie’s Place, which provide support and advocacy for HIV-positive women.</li> <li>– Increasing provider capacity to use peer educators in multidisciplinary care teams.</li> </ul> <p>The LOTUS Project was a collaboration between The Center for Health Training (CHT) and Women Organized to Respond to Life Threatening Disease (WORLD).</p> </li> </ul>
<p><b>Supervision/ Support</b></p>	<ul style="list-style-type: none"> <li>• Christie’s Place leaders consider ongoing training and clinical support and supervision extremely important in navigator effectiveness in assisting clients, job satisfaction, personal mental health, and retention.</li> <li>• Local funding in 2007 enabled the organization to hire a licensed clinician as the Program Manager. This created staff capacity for clinical supervision of peers.</li> <li>• Currently, the organization’s Clinical Director is a Ph.D. and a Licensed Marriage and Family Therapist. She provides an hour of one-on-one clinical supervision for each navigator every week, which navigators consider vital to help them avoid burnout and deal with issues they face, such as transference and countertransference, difficult cases, and other challenges. In addition, there is a one-hour case review session each week that includes all navigators along</li> </ul>

Topic	<p align="center"><b>Christie's Place: CHANGE for Women (C4W)</b>  <b>(Coordinated HIV/AIDS Navigation, Growth and Empowerment)</b></p>
	with other members of the multidisciplinary team including case managers.
<b>Measures of Success</b>	<ul style="list-style-type: none"> <li>Participant demographics, needs and barriers, brief behavioral health assessment, and intimate partner violence and sexual assault – baseline and 6, 12, and 18 months after enrollment in C4W</li> <li>Programmatic outcomes, including level of service engagement, retention in care, and viral load (VL) suppression</li> </ul>
<b>Baseline Data</b>	<p>Of 218 participants:</p> <ul style="list-style-type: none"> <li>Types of clients: 31 newly diagnosed, 54 out-of-care or sub-optimally in care, and 131 at risk of falling out-of-care</li> <li>Needs and barriers: 72% reported food/subsistence needs, 43% transportation, 37% mental health services, 33% housing shelter</li> <li>History: 16% reported intimate partner violence, 23% substance abuse history</li> <li>Characteristics: 95% female, 5% transgender (male to female); 68% women of color; 49% completed high school; 91% under 100% of the federal poverty level; median age 43</li> <li>Retention in care: 57% met continuum of care definition</li> <li>Viral suppression: 73%</li> </ul>
<b>Study/Project Results</b>	<p>For Christie's Place C4W clients with baseline and follow up data:</p> <ul style="list-style-type: none"> <li>23% completed all assessments and 32% completed fewer than 1/3 of scheduled assessments</li> <li>Retention in care increased to 79%</li> <li>For 101 clients with full data, viral load suppression improved to 88%</li> <li>Suppressed viral load at follow up was associated with service engagement level; 98% suppression was found among participants with 3+ assessments versus 77% among participants with &lt;3 assessments</li> </ul> <p>National evaluation data:</p> <ul style="list-style-type: none"> <li>The Social Innovation Fund provides for national and local evaluation. Johns Hopkins University serves as the national evaluator for all the AIDS United sites, and Cardea serves as the local evaluator for Christie's Place. Dr. David Holtgrave at Johns Hopkins has carried out cost-effectiveness analysis of the Christie' Place project that indicates that only 0.82 HIV transmissions need to be averted for C4W to provide cost savings.</li> </ul>
<b>Success Factors</b>	<ul style="list-style-type: none"> <li>Paying navigators a living wage and providing benefits—navigators should not be volunteers</li> <li>Strong training—initial and ongoing</li> <li>Clinical supervision, even though Christie's Place is not a medical provider</li> <li>Use of navigators who are peers, have had many of the same life experiences as their clients, and can tell their story and offer hope</li> <li>Peer empathy with clients and ability to build rapport and trust</li> <li>Being honest with clients about what navigators and Christie's Place can and can't do</li> </ul>
<b>Challenges/ Pitfalls</b>	<ul style="list-style-type: none"> <li>Scarcity of support services for women and their family members</li> <li>Fewer services available due to federal and foundation budget cuts and changes in use of RWHAP funds</li> <li>Immigration status, which limits access to services</li> <li>Difficulty in graduating women out of the program. For most clients, 18 months should be</li> </ul>

Topic	<p align="center"><b>Christie’s Place: CHANGE for Women (C4W)</b>  <b>(Coordinated HIV/AIDS Navigation, Growth and Empowerment)</b></p>
	<p>enough time, but some clients still need help in addressing their barriers, particularly where mental health issues exist and the client does not see herself as “worthy of having a happy life.” They trust and depend on their navigator and resist transfer, even to another navigator. Christie’s Place has a skilled team including a family case worker, so the client can continue to receive Christie’s Place services after C4W navigation services end.</p>
<p><b>Reference/ Contact</b></p>	<ul style="list-style-type: none"> <li>• For more information about use of patient navigators at Christie’s Place, contact Erin Falvey, Ph.D., MFT (Clinical Director) at <a href="mailto:falvey@christiesplace.org">falvey@christiesplace.org</a>.</li> <li>• See the <i>Guide to Integrating Peer Navigators into HIV Models of Care</i>, prepared by AIDS United, the national Social Innovations grantee under which C4W has been partially funded. Completed in May 2015, it is available at: <a href="http://www.aidsunited.org/data/files/Site_18/PeerNav_v8.pdf">http://www.aidsunited.org/data/files/Site_18/PeerNav_v8.pdf</a></li> <li>• Christie’s Place is a part of the AIDS United-CDC prevention capacity-building cooperative agreement, and can provide peer navigation training to CDC grantees through a CRIS request. Contact <a href="mailto:CBA@aidsunited.org">CBA@aidsunited.org</a> for more information.</li> </ul>
<p><b>Observations/ Advice</b></p>	<ul style="list-style-type: none"> <li>• It takes a special kind of person to be a successful peer navigator—they need empathy and patience among other characteristics. Programs need to be very selective in whom they hire.</li> <li>• Christie’s Place has used evaluation results to make program refinements. For example, more than one in four C4W clients reported intimate partner violence/substance abuse, which led to agency training and innovation in trauma-informed care, in order to improve retention in care and viral load suppression.</li> <li>• There is a need for standardized training for navigators statewide that includes agreed-upon topics and leads to a certificate or other credential.</li> <li>• Organizations that have operated navigation programs have learned a great deal; groups developing their first peer navigation program should reach out to these organizations and learn from their experiences.</li> <li>• Every organization is different, and programs run by non-medical providers are likely to be quite different from those run by medical providers. It can be helpful to talk to people in more than one organization to get a sense of what might work best for them.</li> </ul>



Topic	Cascade AIDS Project: CareLink
<b>Organization</b>	Cascade AIDS Project (CAP)
<b>Location(s)</b>	Located in Portland (Multnomah County); serves 5 counties in Oregon and 1 in Southwest Washington
<b>Disease Focus</b>	HIV
<b>Background on Use of Navigators and Specific Projects</b>	<ul style="list-style-type: none"> <li>• Cascade AIDS Project is a large non-medical HIV/AIDS provider that offers prevention and care services, including housing, education, and advocacy. It has more than 60 staff and a budget of over \$6 million.</li> <li>• CareLink, its navigation project, began in 2001, when CAP first received RWHAP Part A funds for EIS. It has evolved over the years, especially during Year 5 of the organization's CDC grant under PS10-1003, which began July 1, 2014. Program refinements requested by CDC led the organization to integrate all CareLink linkage to care services, including navigators funded under RWHAP and CDC, and make them a part of the organization's Prevention and Education Department.</li> <li>• Changes also occurred after CAP discovered that 3-4 partners of its clients had seroconverted during the past calendar year. This led to discussions about how CareLink can prevent this. It was agreed that CareLink needed to do more work with high-risk negatives, providing complementary referral services to the HIV-negative partners of its HIV-positive clients—enabling CareLink to be a supportive and stabilizing force for both partners. CDC prevention funding makes this possible.</li> <li>• The organization has used several behavioral interventions over the years, including Mpowerment, Healthy Relationships, Respect, and ARTAS, and is preparing to implement CLEAR under PS15-1502. It finds ARTAS most useful for clients who need short-term assistance to become linked to care, but have stable housing and a support network.</li> <li>• CareLink includes two navigators supported under RWHAP and 2-3 under CDC, depending on funding.</li> <li>• CAP engages CHWs who are not navigators in a variety of roles. One project similar to CareLink but more specialized is the Mental Health Peer Mentors program. Peer mentors serve HIV-positive individuals who need help with mental health system navigation, linkage to other community supports and resources, and retention in mental health care, medical care, and/or substance abuse services. Clients need not have a mental health diagnosis. Peer mentors engage clients in activities to decrease social isolation, and reduce depression and anxiety related to HIV-related stigma.</li> <li>• CAP has many volunteers, particularly in its Client Services. It has a general open atmosphere but not one-on-one services. In the past CareLink used volunteers, and it may do so again, once the revised CareLink model has been in place for a while. These volunteers are not navigators, but can potentially support and assist navigators.</li> </ul>
<b>Target Population(s)</b>	<ul style="list-style-type: none"> <li>• CareLink primary target populations are people living with HIV who are newly diagnosed, were just released from jail, or have been out of medical care for six months or more. As appropriate, it can also provide services to their high-risk HIV-negative partners.</li> <li>• CAP's target population for HIV testing is MSM.</li> <li>• All newly diagnosed PLWH are offered CareLink services, but the majority of longer-term</li> </ul>

Topic	<b>Cascade AIDS Project: CareLink</b>
	clients are those who struggle to make it to health care, mental health, or substance abuse treatment appointments.
<b>Time Period</b>	CareLink is an ongoing project, currently funded through a combination of RWHAP Part A and CDC funds.
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• Link to care HIV-positive individuals who are newly diagnosed, who have not been in medical care for at least six months, or who are being released from prison or jail, and need assistance connecting to medical care, housing and other services.</li> <li>• Link to education, prevention, and other needed services high-risk HIV-negative individuals, including partners of the HIV-positive individuals served through CareLink.</li> </ul>
<b>Client Barriers Addressed</b>	<p>Most frequently identified barriers include:</p> <ul style="list-style-type: none"> <li>• Mental health problems</li> <li>• Substance abuse</li> <li>• Lack of stable housing</li> <li>• Stigma</li> <li>• Lack of a personal support network</li> </ul>
<b>Service Components</b>	<ul style="list-style-type: none"> <li>• All newly diagnosed PLWH are offered CareLink as their “first stop” on the way to care. Some need only 1-2 meetings, while others need long-term and more intensive assistance.</li> <li>• <b>For high-risk HIV-negatives</b>, focus is on partners of HIV-positives who are served through CareLink, to ensure support needed to keep them negative. Provide education sessions and referrals to needed services, and also enable them to support their partners—for example, by providing bus tickets to both partners when the HIV-positive partner has a medical appointment.</li> <li>• <b>For HIV-positive clients</b>, CareLink focuses on linkage to medical care, medical case management, and assistance in navigating the medical care, mental health care, and drug/alcohol systems. It provides strength-based social services and makes referrals to other needed services. CAP provides services such as behavioral interventions, culturally specific support groups, and housing assistance including housing case management (Portland has a large population of homeless people) and works with clients to address barriers to care. CAP recognizes that social services are necessary for their continued engagement in medical care.</li> <li>• CareLink refers clients to several different medical providers, depending on their needs and where they live. It has a particularly close relationship with the Multnomah County Health Department’s HIV Clinic, an FQHC with a facility located half a block from CAP’s offices. CAP works closely with the County on HIV prevention and care.</li> <li>• CareLink typically provides up to six months of services for high-acuity HIV-positive clients. Some require longer-term support and CareLink uses a client-centered approach, but the project considers it important to “graduate” current clients both in order to take on new clients and to encourage disease self-management.</li> </ul>
<b>Navigator Roles</b>	<p><b>Roles specified in Navigator Position Announcement:</b></p> <ul style="list-style-type: none"> <li>• Provide strengths-based social services to PLWH and assist clients to navigate the medical care, mental healthcare, and drug/alcohol systems and provide support to clients in connecting to housing case management services.</li> </ul>

Topic	Cascade AIDS Project: CareLink
	<ul style="list-style-type: none"> <li>• Collaborate with medical case managers and other support services providers in developing individual goal plans and providing intensive, community-based support to clients in carrying out the activities to achieve their goals.</li> <li>• Develop a comprehensive knowledge of the HIV continuum of care as well as non-HIV specific services available in the Portland metro area.</li> <li>• Complete forms and enter data into the CAP databases in a timely and accurate manner.</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>• Navigators are reminded of their roles and the need to partner with medical providers and medical case managers.</li> <li>• Navigators must understand and maintain client boundaries and confidentiality.</li> </ul>
<b>Navigator Characteristics</b>	<ul style="list-style-type: none"> <li>• CAP looks for culturally diverse individuals to provide linkage to care.</li> <li>• Navigators should include people with a mix of characteristics, such as being gay, HIV-positive, and/or from the communities served.</li> <li>• Important to include people who consider themselves allies of the populations served.</li> <li>• Important characteristics depend on the local epidemic, population served, and project purposes.</li> <li>• CAP needs people who have needed skills and experience as well as a mix of characteristics.</li> </ul>
<b>Navigator Qualifications/ Requirements</b>	<p><b>Required:</b></p> <ul style="list-style-type: none"> <li>• Bachelor's Degree in human/social services field (social work, public or community health, psychology) or related field or equivalent experience</li> <li>• Demonstrated computer and keyboard proficiency using Microsoft Office software (Word, Excel, Outlook) and working knowledge of the Internet</li> <li>• Excellent written and oral communication skills</li> <li>• Successful experience working with ethnic, racial, economic and sexually diverse populations and persons who have experienced homelessness, persons with a mental illness and/or substance addiction</li> <li>• Demonstrated ability to effectively collaborate with community stakeholders</li> <li>• Excellent organizational and time management skills</li> <li>• Ability to work independently with accountability</li> <li>• Available to work occasional evenings and weekends</li> </ul> <p><b>Preferred:</b></p> <ul style="list-style-type: none"> <li>• Previous professional or volunteer experience working with people living with HIV</li> <li>• Knowledge of social services in the Portland metro area</li> <li>• Knowledge of benefits programs available to people with HIV</li> <li>• Verbal and written fluency in English and Spanish</li> <li>• Familiarity and experience with different community services and existing partnerships</li> </ul> <p><b>Other Factors:</b></p> <ul style="list-style-type: none"> <li>• Navigators under RWHAP EIS have very specific contract deliverables, and need case management experience and experience with high-need individuals (e.g., co-occurring</li> </ul>

Topic	Cascade AIDS Project: CareLink
	<p>conditions such as mental health issues, homelessness); HIV experience is not the primary factor.</p> <ul style="list-style-type: none"> <li>• Navigators under CDC have a little more flexibility, and there is more focus on finding people who have worked in HIV or done case management and can provide services on both the individual and group levels (e.g., behavioral interventions).</li> <li>• CAP hires some navigators who are trained social workers.</li> <li>• CAP does not describe its navigators as CHWs, though some would fit the definition.</li> </ul>
<b>Navigator Training</b>	<p>CAP provides several levels and types of training for CareLink navigators, and recognizes that navigators come to the organization with different types and levels of education and experience and therefore have varied training needs. Typically, training for a navigator includes the following components:</p> <ul style="list-style-type: none"> <li>• A shadowing process: new navigators watch and learn from experienced navigators. The team leader decides when the navigator is ready to take on a few clients, and the number increases gradually.</li> <li>• Participation in training provided outside the organization: this includes sessions on topics such as Trauma-informed Care and Motivational Interviewing that are hosted in the community. Expert trainers are available, and navigators participate in sessions with people from other organizations, which provides for multiple perspectives and participant interaction that would be hard to accomplish through internal training when there are only 1-2 navigators being trained. Oregon is one of the few states that has credentialing for CHWs and provides for approved CHW training. CAP does not view its navigators as CHWs, but some of the training sessions could be useful.</li> <li>• Training provided within the organization: CAP provides training to all staff on topics such as HIPAA and confidentiality requirements (one of the first sessions provided as part of the orientation of new staff, with annual updates for all staff); cultural competence around transgender issues; understanding the cultural needs of different racial/ethnic groups; and understanding available resources.</li> </ul>
<b>Supervision and Support</b>	<ul style="list-style-type: none"> <li>• Two types of supervision are provided: <ul style="list-style-type: none"> <li>– A Program Manager with strong management and program implementation skills provides administrative supervision; this person oversees CareLink and ensures that deliverables and other contract requirements are met.</li> <li>– A Team Lead (a current MSW student and previously a navigator) who also has strong skills in resource navigation provides technical supervision and oversight.</li> </ul> </li> <li>• Navigators as a group have a weekly check in with the Team Lead and Manager that is used for discussion of difficult cases and other issues related to their assistance to clients.</li> <li>• At least every other week each navigator receives individual supervision through a meeting including both supervisors.</li> </ul>
<b>Measures of Success</b>	<ul style="list-style-type: none"> <li>• CareLink documents services such as number of clients referred to medical care and other services and number who actually accessed those services; includes actual linkage to partner services.</li> <li>• It can be especially difficult to do follow up beyond the initial appointment, especially for high-risk negatives and the newly diagnosed. MOUs call for such information to be reported,</li> </ul>

Topic	Cascade AIDS Project: CareLink
	<p>but this can be difficult.</p> <ul style="list-style-type: none"> <li>The project is not monitoring medical outcomes such as viral suppression, though it hopes to do so in the future; this can be challenging for a non-medical provider that makes referrals to multiple medical providers.</li> <li>Follow up with the Multnomah County Health Department on RWHAP EIS clients is easier, since the county provides the EIS funding.</li> <li>CAP would like to do more research involving the CareLink model.</li> </ul>
<b>Baseline Data</b>	N/A
<b>Study/Project Results</b>	<p>Available information indicates that CareLink is:</p> <ul style="list-style-type: none"> <li>Successfully linking clients to medical care.</li> <li>Doing very well in getting clients the services they need, though there are some limitations in service availability.</li> <li>Following up with clients.</li> <li>Successfully using a client-centered approach.</li> </ul>
<b>Success Factors</b>	<p>The following have been important success factors for CareLink:</p> <ul style="list-style-type: none"> <li>Its commitment to regularly re-evaluating the project and making changes to address identified challenges and changing needs.</li> <li>Establishing strong partnerships with medical providers has been an important positive factor. CAP has been fortunate to have good relationships, particularly with the county clinic.</li> <li>Portland has a very high success rate in linking clients to medical care, and there is a shared commitment to linkage.</li> <li>CAP is well situated physically, which facilitates linkages. Being very close to one of the nation's largest FQHCs is very helpful. When partner agencies are located close together, it is almost like having a "one-stop shop." In addition, Portland is a relatively small metro area.</li> <li>Finding the right staff has been very important, and of course looks different for each program and community.</li> </ul>
<b>Challenges/ Pitfalls</b>	Client-centered organizations with highly committed staff sometimes design projects that are unreasonably demanding, setting objectives that cannot reasonably be met.
<b>Reference/ Contact</b>	For more information and copies of forms and other materials that may be useful to other navigation programs, contact Caitlin Wells, Director of Prevention and Education Services, at 503-278-3860, email <a href="mailto:cwells@cascadeaids.org">cwells@cascadeaids.org</a> .
<b>Observations/ Advice</b>	<ul style="list-style-type: none"> <li>Take the time to determine what your program should look like, based on your clients and community. After implementing, pause and take the time to evaluate and re-evaluate on a regular basis; stop and say, "Is this still working?" When you make changes, be sure staff know why they are being made.</li> <li>Know whom you are going to be serving, and find the right navigators for your program. For example, if you have many clients with mental health and substance abuse issues, be sure your navigators are prepared to work effectively with such clients.</li> </ul>

Topic	Cascade AIDS Project: CareLink
	<ul style="list-style-type: none"> <li>Know the other agencies you can reach out to for advice and assistance. Don't waste time recreating forms and paperwork that a peer organization may be happy to share.</li> </ul>

### Learning from the Models

You will probably want to learn and borrow from several different models. The table below helps you identify and note the most useful or transferable information from the models profiled in this chapter. Use the last column to flag components about which you are still uncertain—perhaps you need more information before making a decision, or will need to consult with other stakeholders.

Program Component	Profiled Models of Interest	Ideas/Lessons from These Models	Remaining Questions/ Issues
Target Population(s)			
Navigator Roles and Limits			
Navigator Characteristics			
Navigator Qualifications			
Navigator Training			
Navigator Supervision and Support			
Relationships with Other Providers			
Performance and Outcomes Measures			
Other			

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## CHAPTER 6: INCORPORATING PN PROGRAMS INTO YOUR HIGH-IMPACT HIV PREVENTION PROGRAM

### Objectives:

1. To identify factors to consider as you plan how to incorporate a PN program into your HIV prevention program
2. To help you obtain “buy in” and support for your navigators from key stakeholders, both within your organization and at partner organizations such as medical/clinical and supportive services providers
3. To determine your PN program’s scope, components, and navigator roles.
4. To ensure that your program meets national and state/local legal requirements and HIPAA and confidentiality standards
5. To use best practices in program development and in the recruitment, selection, supervision, career development, and retention of your patient navigators
6. To provide suggested steps for developing your PN program and ensuring it is fully integrated into your prevention program
7. To know where to go for information and advice that will help ensure an effective PN program

### Designing Your PN Program

You now have a good sense of both the core components and the varied models for PN programs using community navigators. You also know that your PN program can help link HIV-positive individuals to care and then help them address barriers so they stay in care and achieve viral suppression. It can also link high-risk HIV-negative people to prevention and other services that help them stay negative.

If you are developing a PN program to meet the requirements of CDC FOA PS15-1502, you will need your PN program to be operational and integrated into your prevention program within six months after grant award. If you already operate a PN program or have community health workers who carry out similar tasks, you may need to refine current strategies so your program reflects best practices and meets CDC expectations. Here are some factors to consider as you begin to design your program:

1. **The purpose of your PN program—what you want it to accomplish:** You need to meet the needs of the CDC grant, but beyond that, how can a PN program strengthen your ability to find and serve high-risk HIV-negative and HIV-positive people, help ensure they get the services they need, and stay negative or become virally suppressed? Are there gaps in the HIV continuum they can help fill? Particular populations they need to reach and serve? How can they reduce the burden on medical personnel or case managers? You probably made some of those decisions in preparing your PS15-1502 proposal, so you might start with program purpose and focus as described in that proposal.

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In San Diego County in 2010, an estimated 69% of women with HIV who knew their status were not in care—so Christie's Place trained and engaged peer navigators to find out-of-care HIV-positive women, help them enter or re-enter medical care, and improve retention in care.

2. **Your current use of community navigators or similar personnel:** If your organization already uses CHWs but not as navigators, or if you have a PN program but feel it needs to be changed to meet the needs of the CDC grant, consider whether to build on that base or establish a new PN program. Benefits of building on current activities could include a quicker process, some experience to build on, experienced navigators who may need only some additional training, and the opportunity to make navigation a greater part of your service model. Challenges could arise if the needed changes seem incompatible with the program as currently designed and implemented, or if you encounter serious resistance to change from current program administrators or current staff with roles similar to those of navigators.
3. **How the PN program fits into your high-impact prevention program:** Since your navigator program is a part of your new or existing high-impact prevention program, carefully consider: how it will “fit” in terms of staff supervision and interaction, when and how clients will be referred to navigators, where it fits in the organizational chart, how the navigation component will communicate with other components, and how it can support the overall effort. Involve staff from other parts of the prevention program and related programs to be part of the planning, and ask for input from other project staff.
4. **Who needs to be part of the design and planning process:** Some of your staff and/or external stakeholders may need to be involved because they bring important experience and expertise. Prevention program staff need to be involved to ensure that the program becomes an integral part of that program. If you are a non-medical provider that will be working with a particular clinical provider such as an FQHC or health care system, you may want the involvement of that partner. If someone from your area's AIDS Education and Training Center (AETC) or the research unit of a local school of public health has helped in PN program design, training, or evaluation, that person may be a valuable advisor. In addition, involving certain staff, volunteers, or external stakeholders in the planning may help you obtain their support for the PN program. Consider how best to engage them. You might consult with them individually or hold a group meeting to get their input. A small planning team of two to four people might do most of the work, involving others at the beginning to offer advice and at the end to review your proposed program.
5. **What resources you have to support your PN program:** Resources will necessarily affect the design of your PN program. This includes the size of your new CDC grant and the amount allocated to PN, the amount and types of other HIV funding for linkage to and retention in care, and other funding that helps support patient navigation or related



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services. Resources will influence both the number of navigators and your PN program model.

- 6. What you see as the most important benefits of having navigators:** Your experience—and your knowledge of the HIV care continuum/treatment cascade for your clients or your geographic area—may lead you to feel that navigators are most important in getting newly diagnosed people into care within 90 days following diagnosis. If you know that prompt linkage is happening but retention in care is a problem, your focus may need to be on retention. Or a high estimate of “unmet need” may indicate that priority should be on finding HIV-positive people who are out of care so they can be linked or re-linked to a medical provider and a case manager. It helps to know your strengths and weaknesses and identify the benefits you most need from your PN program.
- 7. Your greatest concerns:** As discussed in Chapter 4, the better you understand the challenges and potential pitfalls of a PN program for your organization, the more likely you are to avoid or minimize them through appropriate project design. Consider expected challenges, how profiled model projects have addressed them, and how you plan to address them. The table below can help you summarize this information.

Your Greatest Concerns	Ways Model Projects Addressed This Concern	How You Plan to Address this Concern

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Use the chart below to summarize your thoughts about the topics listed above—and any others you feel need early consideration as you begin developing your PN program.

<b>Factors to Consider in PN Program Planning</b>			
<b>Topic</b>	<b>Your Thoughts</b>	<b>Notes from the Profiled Models</b>	<b>Additional Input/Information Needs</b>
Purpose of your PN program			
Current use of navigators or similar personnel			
Integrating PN into your prevention program			
Who should be part of the planning process			
Available resources			
Most important benefits of having navigators			
Greatest concerns			
Other			

## **Getting Organizational Buy-in**

PN programs are most effective when well integrated into the overall work of the organization as well as your prevention program. Being an informed member of the HIV service team is important for patient navigators, as indicated by the programs profiled in Chapters 4 and 5 of this guide. If your organization is a medical provider, work with clinicians to obtain their support for the navigator role. If you are not a medical provider, ensuring buy-in from the medical provider who serves your clients is just as important.

One non-medical provider found that some doctors at its partner clinics resisted working with navigators. The PN program was ensured thorough training and effective supervision. Their navigators built trust with clients, who began to share barriers and concerns that they did not share with the other members of their treatment team. The navigators shared this information with clinicians at case review meetings, and clinicians found it useful in providing care. At a meeting held 18 months after the PN program began, one of the doctors who had been most resistant to navigators announced his hope that in the future, all his HIV patients would have a navigator.

## **Addressing Legal Requirements**

In most states, there are no special legal requirements that affect the hiring of navigators or other CHWs. However, there may be requirements that apply to all your employees or certain categories of employees that include navigators. Be sure to identify any requirements that may affect navigators in your location.

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**Background checks:** Be sure you are following state and municipal requirements for employee background checks. Some employers are required by state or local laws—or by their internal policies—to conduct background checks of all employees. This is most commonly required for employees who work for health or human services providers, offer certain types of services, serve children, or provide home- or community-based services. Individuals who have been convicted of felony sex offenses, murder, domestic abuse, and some other violent crimes may be excluded from employment. Additional exclusions may apply to navigators employed by public agencies such as public clinics or universities—and sometimes their contractors or subcontractors.

If your navigators do home visits, they may be covered by regulations for in-home care workers. A 2014 report by the U.S. Department of Health and Human Services found that background checks are often optional or incomplete even for in-home care workers. The federal government does not require background checks or specify situations excluding individuals from such employment. Only 11 states require “full, comprehensive background checks.”<sup>52</sup> There is even less consistency regarding background checks for community health workers not providing in-home services.

Additional exclusions—for example, individuals convicted of a drug offense or anyone convicted of a felony with the last X years (depending on the state)—can negatively affect organizations that hire peer navigators. If your organization wants its navigators to “look like” its clients and share similar life experiences, you will not want to exclude an applicant because of a criminal history or past substance abuse—so long as it is in the past and is not relevant to the work.

Be sure you know the requirements for background checks, including:

- **Scope:** What information must be sought, what databases must be used, and whether fingerprints are required.
- **Frequency:** Whether the background check must be done only at the time an employee is hired, or whether it must be repeated every few years after that.
- **Situations that can exclude them from employment:** What criminal convictions or other findings can exclude a person, and whether years since conviction matter.
- **The process for gaining an exception to exclusion:** How you can make a formal request for permission to hire a person with an excludable conviction; this is particularly important where almost any criminal convictions is a cause for exclusion—which may be the case in some public hospitals and universities, for example.

**CHW Regulations:** A paraprofessional/community navigator is usually viewed as a type of CHW. Relatively few states regulate CHWs, but the number is increasing. As of 2014, CHWs—including

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<sup>52</sup> See “Background Checks for Care Providers are Often Optional,” Scioto, at <http://www.scioto.com/background-checks-care-providers-often-optional/> or Shaun Heasley, “Background Checks for In-Home Care Workers Often Optional,” Disability Scoop, June 6, 2014, at <http://www.disabilityscoop.com/2014/06/06/background-checks-optional/19421/>

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community navigators—who provide services in Ohio, Oregon, or Texas must meet state regulations, and Massachusetts is in the process of developing regulations.<sup>53</sup>

**Credentialing:** An increasing number of states offer some form of CHW credentialing, and patient navigation is included as a role for CHWs in most of these states. Navigators are not separately credentialed by states, although some navigator training entities, including institutions of higher education, do provide certificates to their graduates. States are more likely to provide credentialing than regulations, but the two are sometimes related. States that permit Medicaid reimbursement for services provided by CHWs often require that these CHWs have a defined level of training or experience. Helping your navigators obtain available certification can increase their status and credibility with clinicians, other partners, and clients. Certification requires training that has state approval, for which experience can sometimes be substituted.<sup>54</sup>

**Insurance:** Ensuring that clients get to their appointments is a common role for patient navigators. They may accompany clients, especially to the first few appointments, and some navigators drive clients to these appointments. This is particularly common in areas with poor or no public transportation. In planning your PN program, be sure to consult with a knowledgeable insurance representative before deciding how to arrange such client assistance, so that both you and your employees are protected in case of property damage, injury, and lawsuits if an accident occurs. The insurance issue is extremely complex and subject to multiple interpretations.<sup>55</sup>

It is generally agreed that if your navigators drive vehicles owned by your organization, you need commercial auto insurance that adds employees as “additional insured.” If the navigators may sometimes use a rental car or their own vehicle, your policy must cover “non-owned” and “hired” vehicles. Other coverage may also be needed, depending on the state.

If your navigators drive their own vehicles, they also need appropriate insurance. If a navigator has an accident while driving his/her own car for work-related purposes, the navigator’s personal auto insurance is generally considered the “primary” insurance, even if you have appropriate employer insurance; your policy is used only if the costs exceed the limits of the navigator’s insurance or if someone involved in the accident sues your organization and your

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<sup>53</sup> See the state-based chart, “State Community Health Worker Models,” which describes CHW funding, education, certification, legislation, organizations, and role in the state, prepared in early June, 2015 but periodically updated, on the State Refor(um) website: <https://www.statereforum.org/state-community-health-worker-models>. Also see Peyton Miller, Taylor Bates, and Amy Katzen, “Community Health Worker Credentialing: State Approaches,” Harvard Center for Health Law, Policy & Innovation, School of Law, June 6, 2014. Available at: <http://www.chlpi.org/wp-content/uploads/2014/06/CHW-Credentialing-Paper.pdf>

<sup>54</sup> Harvard Center, *Ibid*.

<sup>55</sup> See, for example, “Business Use of Employee’s Autos – An Insurance Perspective,” at <http://www.scottsimmonds.com/blog/business-insurance/employee-auto/>, and “Employer Non-Owned Car Liability Coverage,” at <http://businessinsure.about.com/od/commercialauto/a/Employer-Non-Owned-Car-Liability-Coverage.htm>

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employee. If transporting a client is interpreted as providing a “vehicle for hire,” the navigator’s personal insurance company may refuse to pay unless the navigator has commercial auto insurance. Your navigators should be made aware of these insurance issues and how you are handling them, including the likelihood that their own insurance will be used first in case of an accident.

If you expect your navigators to use their own vehicles to transport clients or carry out other work-related tasks, it is your responsibility to ensure that such employees have a valid driver’s license and appropriate insurance. The box below provides language from the job requirements section of a position announcement for a navigator who is expected to use a personal vehicle.

Providers typically provide local travel reimbursement when navigators use their vehicles for work-related activities; this is usually based on the number of miles driven. One reason for paying the full per-mile reimbursement permitted by a federal, state, or local government funder is that this rate is designed to cover the costs of gas, maintenance, and insurance.

**Requirement in a Peer Navigator Job Announcement, Christie’s Place, San Diego:**

*It is required that a Peer Navigator possess a valid Driver’s License with access to reliable personal transportation, as well as proof of current vehicle insurance in good standing.*

## **Managing HIPAA and Confidentiality Issues**

Patient navigators nearly always need access to some patient health information. As their employer, it is your responsibility to ensure that they comply with the requirements of HIPAA, state requirements, and your organization’s own confidentiality rules.

- *If you are a medical provider, you almost certainly already have both HIPAA and other confidentiality rules and procedures in place, including policies for ensuring that navigators (like other staff) receive appropriate HIPAA and confidentiality training.*
- *If you are a clinical provider offering mental health or substance abuse services but not primary care, you are also covered by HIPAA and should have rules and procedures in place. In fact, the disclosure requirements related to mental health records, psychotherapy notes, and alcohol and substance abuse records are especially strict in most states.*
- *If you are not a clinical provider and will be partnering with a clinic or other provider of HIV medical care, or if the only clinical data you receive involve HIV test results, you may need to develop or enhance your HIPAA and confidentiality policies and procedures, and/or provide additional training for your navigators.*

Whatever your situation, your navigators will need training and periodic “refreshers” on their responsibilities for meeting HIPAA and other privacy and confidentiality requirements and best practices.

The HIPAA Privacy Rule requires covered entities (such as health care providers) to maintain and protect the privacy and security of individually identifiable protected health

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information (PHI) that is transmitted electronically. PHI is defined as “protected” because of the content of the information, whether it is in electronic, written, oral, or any other form. Navigators are likely to have access to PHI such as an individual’s HIV test result and the results of other laboratory tests, other diagnostic information, information on prescriptions and other aspects of treatment, names of clinicians serving the client, and personal information such as address, telephone number, and birthdate. Many navigators have full access to their clients’ electronic health records.

Your navigator is also extremely likely to be engaged in activities covered by HIPAA and other confidentiality protections, such as linking the client to a physician, other clinicians, and support services; helping to ensure that medical appointments are kept; and helping the client prepare for medical visits. In most programs, navigators are expected to have each client complete a confidentiality and disclosure form that clearly specifies what information can be shared, with whom, and for what purposes. The client signs and dates the form, and it must be renewed periodically.

Clients and clinicians should be confident that navigators are familiar with issues of privacy and confidentiality including HIPAA requirements, have received appropriate training, and are aware of situations that require special attention and care. For example:

- In texting a client an appointment reminder, the name of the doctor should not be included.
- If the navigator has health information to share, a voice mail or text should ask for a return call or meeting, but not put the information in the message.
- Clients should be asked if there is a specific telephone number or email address or a particular method that should be used for communications from the navigator.
- In a provider facility, PHI, including the client’s HIV diagnosis, should never be discussed in a public location where it might be overheard.
- The navigator should not share PHI with a client’s family members or friends unless the client has agreed to this.
- The navigator should not access a client’s EHR in an area without privacy, and PHI should never be left visible on a computer screen when the navigator is not present.
- If any possible breach or failure in safeguarding PHI occurs, the navigator should report it immediately to the supervisor. This can help minimize any resulting problems.

In planning your PN program, also consider whether your partner organizations have appropriate HIPAA and other privacy/confidentiality protections. Perhaps some of their staff would benefit from the same training you provide to navigators. Sometimes, if you contract with another entity, you will need to take responsibility for ensuring HIPAA compliance by that partner through a written, signed “Business Associate” agreement.

For more information on HIPAA and other confidentiality and privacy issues important for PN programs, as well as tools useful for training your employees, see the following:

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- The Department of Health and Human Services webpage and supplemental information, at: <http://www.hhs.gov/ocr/privacy/hipaa/understanding/>
  - The HIPAA regulations revised and with administrative simplification text as of 2006, including the HIPAA Omnibus Final Rule issued on January 17, 2013, at: <http://www.hipaasurvivalguide.com/hipaa-regulations/hipaa-regulations.php>
  - A PowerPoint presentation called “Privacy for Beginners: What every Healthcare Worker Needs to Know About HIPAA and Privacy,” prepared by hcPro and available at: <http://www.mclaren.org/uploads/public/documents/bayregion/documents/bavc/securitytrainingvolunteerclinic.pdf>

## Hiring and Managing Patient Navigators: Human Resource Issues

PN managers and HIV interdisciplinary teams agree that among the most important success or failure factors for PN programs is a well thought out, carefully implemented process for recruiting, hiring, training, and supporting your navigators. As the diversity among Chapter 5 profiled models indicates, there is no single “right” way to address human resource (HR) issues related to PN programs, but there are some strategies that have worked well for other programs—and some actions to avoid.

- **Job Qualifications:** PN programs differ in their job qualifications for navigators. Many programs consider knowledge of, and experience working within, the local HIV and health care and human services systems to be more important than level of formal education.

One provider in a rural area describes the program’s patient navigator as its “lifeline”—the navigator grew up in the community being served and is familiar with local service providers, service gaps, and challenges that residents face. The navigator has been able to develop trust with clients and service providers and can be relied on for sound program advice.

Some programs hire only peer navigators. Others view the term “peer” as involving similarities to their clients with regard to race/ethnicity, gender, gender orientation, and life experience, rather than or in addition to disease status. Still others do not require that navigators be peers in either sense. Research indicates that the effectiveness of PN programs is increased when programs look for navigators who reflect the diversity of their clients and have considerable familiarity with their life experiences and communities. As the Community Health Worker Section of the American Public Health Association (APHA) puts it, CHWs including community navigators are “frontline public health workers who are trusted members of and/or have an unusually close understanding of the community served.”<sup>56</sup>

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<sup>56</sup> As quoted in CDC’s *Addressing Chronic Disease through Community Health Workers: A Systems Level Approach*, 2nd edition, April 2015. See [http://www.cdc.gov/dhdsp/docs/chw\\_brief.pdf](http://www.cdc.gov/dhdsp/docs/chw_brief.pdf)

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Many PN programs look for personal characteristics as well as training or work experience in developing job qualifications. Consider whether you want to include characteristics such as empathy, commitment to the community, tact, flexibility, and trustworthiness as desired qualifications—and how you might use personal references or responses to scenarios to assess applicants based on these characteristics. *Include only qualifications you can assess during the hiring process.*

- **Position Announcement:** Most organizations have a template for position announcements. You may want your position description for a patient navigator to be unusually detailed, since there is no single definition of what such a job entails, and you want applicants to understand your expectations. It is helpful to describe the organization and the PN program, state desired characteristics, job requirements, and responsibilities, and provide an equal opportunity statement, which may go beyond federal requirements—for example, including nondiscrimination on the basis of sexual orientation and sexual identity. Be sure to provide instructions on applying for the position. Job announcements or position descriptions for navigators are usually available online; for examples, just use your search engine to find “Patient Navigator Jobs” or “Peer Navigator Jobs.”<sup>57</sup>
- **Application Requirements:** Ask applicants to apply for the position in a way that is likely to encourage the right applicants to apply, and to get you the information needed for assessing their “fit” with your position requirements and preferences. Since community applicants may not be experienced in preparing resumes, one approach is to ask them to send a letter describing how they meet the job qualifications and can carry out the roles specified in the position description. Some organizations make the resume optional. Using an organizational application form can be useful as well. You might ask applicants to provide letters of recommendation from community leaders or service providers, which will help you learn about their community contacts and personal characteristics. The box below provides application instructions included in a Cascade AIDS Project CareLink Network Navigator job announcement.

**Apply for this position, mail, email or deliver the following three documents:**

- 1) Your resume, 2) a cover letter that addresses how you meet the minimum qualifications specific to the position you are applying for, and 3) a completed CAP employment application (available at [www.cascadeaids.org](http://www.cascadeaids.org)).

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<sup>57</sup> An archived job announcement for a peer navigator for the CORE Center HIV/AIDS Project in Chicago is available at <http://www.gettinghired.com/jt3036835-Patient-Navigator-Core-Center-HIV-AIDS-Project-I-Chicago-IL.aspx>



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- **Recruitment Strategies and Tools:** Recruitment of community navigators can be easy if your organization has a history of employing paraprofessionals from the community, and more difficult if it does not. Allow yourself enough time to identify a good pool of candidates. Ideally, post the position 6-8 weeks before it needs to be filled. In addition to posting with the state and/or local employment service, consider the following recruitment sources and methods:
    - **Internal recruitment:** If you already employ CHWs in non-navigation roles, do internal recruitment, and encourage current navigators and other CHWs to disseminate the job announcement. Several of the profiled programs said they often promote a current CHW employee to a navigator position after 2-3 years in a position that helps them learn about HIV prevention and care, become familiar with HIV and social service providers, and demonstrate skills and personal characteristics needed for successful performance as a navigator.
    - **Organizations that employ or work with community navigators or other CHWs:** Send the job announcement to contacts at organizations where a posting is likely to be seen by qualified individuals; for example: FQHCs and other clinics, health systems providing HIV services, mental health and substance abuse service providers, supportive service providers and other community-based organizations, and local PLWH groups. Suggest that organizations share the job description with their Patient Advisory Councils and—for community-based groups—volunteer peer leaders and Boards of Directors. HIV Prevention planning groups and Ryan White HIV planning councils typically include CHWs and/or work with them; encourage members to share the job description with them.
    - **Personal outreach:** If you send a personal email or—better yet—talk directly to leaders or staff of the kinds of groups identified above, they are more likely to take the time to think about and refer possible candidates. Ask members of your staff who interact with such organizations to make personal contacts and ask about possible applicants. While they may not want to encourage valued employees to leave them to work for you, they may be able to identify and link you to board members, former staff, contacts at other agencies, or current staff in dead-end positions.
    - **CHW groups:** Send your position announcement to state or local community health worker associations; they now exist in at least 25 states and the District of Columbia. If someone in your organization is a member of the American Public Health Association, contact the Community Health Worker Section.<sup>58</sup> A list of state and national CHW associations as of early 2015—with contact information—is provided

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<sup>58</sup> Website identifies Section leadership. See [www.apha.org/apha-communities/member-sections/community-health-workers](http://www.apha.org/apha-communities/member-sections/community-health-workers)

in the new edition of CDC's *Addressing Chronic Disease through Community Health Workers: A Systems Level Approach*.<sup>59</sup>

- **Social media:** Post the job announcement on your website and disseminate the link to your electronic networks through blog postings, Facebook, Twitter, and other social media platforms.
- **Traditional media:** Newspapers can be helpful in recruitment; consider both paper and electronic options. Often the most useful sources are community newspapers, especially the racial/ethnic press.
- **Selection:** Application review, interviews, and selection of your navigator require care and thoroughness. If you have an established selection process that has led to the employment of qualified professional and paraprofessional employees who are successful in their work, use it—perhaps with some refinements or special areas of emphasis. If not, the following approach may be helpful:
  - Be sure your position announcement is clear about required and preferred qualifications and personal characteristics, and evaluate applicants based on them.
  - Develop a chart or other tool and use it consistently to review each application against the requirements and preferences stated in your job announcement. One useful format is the following, which uses a separate sheet for each applicant:

<b>Navigator Applicant Review Sheet</b>		
<b>Applicant Name/Number:</b> Mary Doe		<b>Name of Initial Reviewer:</b> John Smith
<b>Job Requirement or Preference</b>	<b>Rating: 3, 2, 1, or 0*</b>	<b>Notes/Recommendations</b>
≥ 1 yr. of experience working in HIV	3	2 years doing outreach for HIV prevention and testing
Computer skills—Microsoft Office; electronic health records or client-level database	2	Microsoft Office—yes EHR/database—very limited, but indicates taking several computer courses
Knowledge of community X	3	Has lived here all her life; volunteer experience with several human service organizations
ETC.		
Other Observations		Letter indicates a high level of interest in navigator position and a high level of community involvement
Mean Rating	2.67	Definitely interview

\* 3 = High/fully meets requirement or preference; 2 = Medium/partly meets requirement or preference; 1 = Low/ does not appear to meet requirement or preference; 0 = Insufficient information to rate applicant on this requirement or preference

- If initial review responsibilities are shared, hold a pre-review meeting of the individuals involved. Discuss the process to be used and the method of

<sup>59</sup> Previously referenced. See pages 17-19. Available at [http://www.cdc.gov/dhdsp/docs/chw\\_brief.pdf](http://www.cdc.gov/dhdsp/docs/chw_brief.pdf)

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- documentation, and be sure there is agreement on interpretation of the criteria so they can be applied consistently.
- Once initial reviews are complete, review the charts or other notes, and eliminate individuals that clearly do not meet the requirements.
  - If you still have a large number of applicants—too many to interview—have the initial reviewers look together at “borderline” applicants and eliminate those that do not meet most of the preferred as well as the required qualifications. When uncertain, keep the application.
  - If the number of applicants is still large for individual interviews, consider brief 10-15 minute telephone interviews using a consistent set of questions to further explore the extent to which the applicant possesses both required and preferred qualifications and characteristics.
  - Choose the most promising applicants and bring them in for personal interviews. Ask them to provide references (preferably people they have worked for or with), ideally three of them. You may want to check references before the interview, to identify areas that should be explored in the interview.
  - Use a set of consistent questions for all applicant interviews, as well as clarifying questions to address incomplete or unclear information in the application. If possible, involve an experienced navigator and another key project staff member in the interview. If this is not possible, consider a two-stage process where the probable hire, or perhaps two top candidates, come in a second time to be introduced to the project team.
  - Consider using scenarios to find out how applicants would handle situations that might arise in their work, and how well they understand navigator roles and boundaries. Several possible scenarios are provided in the box. Construct scenarios that get at how the applicant might address issues of particular importance to your program and discuss what you consider to be desirable responses. Ask each applicant to address at least one of these scenarios, and take notes on the responses you receive.

### **Sample Scenarios for Navigator Interviews**

#### **1. Understanding Roles and Limits**

Let's assume you have been working as a patient navigator for about four months. One of your recently assigned clients is very open with you but seems to have a lot of trouble communicating with her HIV doctor. She comes to you one day to tell you about side effects she is having with a particular medication, and wants to know if she should change the way she takes the medication, or whether she might be getting too high a dose. She really wants you to advise her, and she just saw the doctor last week so isn't planning for another visit for several months. You are actually quite familiar with the medication and its side effects. What should you do to help?

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## 2. Working with a Multi-disciplinary Team

As a relatively new navigator, you know you have to prove yourself to other staff, especially clinical staff. You feel that one of the case managers housed at the clinic serving most of your clients really does not want to work with you. The HIV doctor and nurse practitioner have begun asking you for information and assistance with some of your clients – for example, asking you to help one client prepare questions before a medical appointment,

suggesting that you arrange for another to participate in a support group for recently diagnosed older adults, etc. But the medical case manager, who is a social worker, has not asked you for any help, and has rarely provided any information or support. What might be causing this situation, and how might you address it?

## 3. Disease Self-Management

You have been working with a particular client for about five months. In the beginning, he had a very low level of trust and told you – and everyone else involved in his treatment – very little. But you have worked with him closely and supportively over the last few months. He has told you about some important family-related barriers to care, taken your advice regarding how to cope with some personal issues, and followed his treatment plan. He now contacts you every day or two, always with a meaningful question or request. What are some proactive things you might begin to do with this client?

- Be sure to describe your PN program, expectations for navigators, any special requirements such as having a valid driver’s license or being able to work evenings or weekends. Talk about requirements for documentation and use of technology. Also explain salary and benefits, training, and supervision to minimize uncertainty about the job.
- Have someone take notes on responses during the interviews, perhaps using a form similar to the Navigator Application Review Sheet that lists questions and provides room for notes. Take a few minutes after each interview to debrief on how well the applicant fits your requirements and expectations, perhaps by providing a numerical assessment.
- Once you make a hiring decision, follow up with other strong candidates; you may need one of them in the future and want them to know you value their time and interest.
- **Training and Staff Development:** As most of the profiled projects made clear, your arrangements for navigator training, other professional development, and support are very important in determining navigator success and retention. Navigators typically need training before they begin work with clients, active mentoring and support during the first 3-6 months on the job, and ongoing in-service training and other staff development—including opportunities to share experiences with other navigators and to participate in case conferences about their clients.

Prior experience with HIV prevention and care may reduce the need for navigator core competencies or HIV training. However, navigators still need training to develop knowledge and skills related to your program’s service and navigation model and

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strategies. For example, you may expect your navigators to use Motivational Interviewing and/or apply Stanford Chronic Disease Self Management techniques. They will also need to understand your protocols, be prepared to interact with clinical staff, and be prepared to document their work through the appropriate EHRs or other data bases or paper forms. Even if they have received HIPAA training, they will need to understand your organization’s policies and protocols on data sharing, privacy, and confidentiality. Be sure your training plan takes advantage of existing training opportunities for some types of skills, and provide in-house training to fill the gaps. In your planning, try to “build in” learning experiences through case conferences with your project team, in-service sessions including “refreshers” on topics like HIPAA and updates on changes in the HIV prevention and care system or new project strategies.

### **Scheduling Regular In-Service Training**

Providing regular in-service training for navigators (and other staff!) can be difficult to accomplish while you are providing services to clients. Several community-based AIDS Service Organizations (ASOs), both clinics and non-medical providers, report that they close their facility to clients one day a month to provide time for staff training and other types of career development.

- **Supervision:** Be sure your navigators receive supervision from someone with the time, skills, and interest to provide supervision and support and the ability to help integrate PN services into your prevention program. If the supervisor is not a clinician, find a way for navigators to receive regular advice and support from a clinician.

**Addressing Other Organizational Needs:** In planning your PN program, consider other organizational needs, such as the following:

- **Setting wages and determining benefits.** Get good human resources advice on wages and benefits for your patient navigators. If your navigators work full time, presumably they will have the same benefits as other staff. If you want to compete for talented navigators and retain them once trained and experienced, you will need to offer fair and competitive wages. If you want part-time navigators, ensure that they have continued access to health care. Consider whether your insurance provider allows you to offer health insurance to part-time employees and if so, how many hours per week they must work to be eligible; whether navigators now receiving medical care and medications through the Ryan White HIV/AIDS Program will maintain eligibility once you employ them; and whether you should structure positions so navigators remain eligible for Medicaid, disability, and/or government subsidies for insurance purchased under the Marketplace of the ACA.
- **Documenting navigator activities and program results.** Your navigators will be providing information and assistance to your program clients that needs to be accessible to other members of your project team, both to support their work and to ensure information needed for management and supervision. If you use EHRs or some other

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type of client-level database, you probably will want your navigators to record their client-related activities directly into your existing system. If you do not have an EHR or other client database, you will need to decide both what navigator activities you want documented and what electronic or hard-copy forms you want used.

Most programs document the results of navigation and other services. Usually, this includes measures like the number of HIV-positive or high-risk HIV-negative people linked to HIV-related medical care or other specified services within 90 days (or some shorter period of time) after diagnosis, what proportion of clients are retained in care as determined by number of doctor visits or other indicators of being in care, and what proportion of HIV-positive clients are virally suppressed. If you are measuring the “value added” of a new program, you may want time-based measures that indicate client status before and after implementation of your navigator services, or comparative measures for clients who do and do not receive navigation services (intervention and control or comparison groups). Obtaining appropriate data, especially comparative data, requires agreeing on documentation and evaluation measures as you plan your program.

- **Preparing your staff:** If navigators are your organization’s first community staff, or the first in your HIV prevention program, be sure to prepare your staff to welcome and interact positively with your navigators. One useful approach is to provide training to all staff, and perhaps special or additional sessions with clinical staff, so they understand navigator roles and how to obtain maximum benefit from working with navigators.

### Step-by-Step PN Program Planning and Implementation

As discussed, developing your first PN program takes time, consultation, and consideration of a number of issues and possibilities. The chart below provides a suggested step-by-step process or work plan for PN program planning and start-up that integrates information presented in this chapter and in earlier sections of the Guide. Modify this chart as needed and try using it in developing your “plan to plan.”

<b>Suggested Steps in Planning and Initiating a Patient Navigation Program</b>		
<b>Step</b>	<b>Components/Factors to Consider</b>	<b>Notes</b>
1. Establish a planning group	<ul style="list-style-type: none"><li>● Include a clinician if possible.</li><li>● Consider including a navigator or CHW.</li><li>● Seek advice from partners and other stakeholders whose support your navigators will need.</li></ul>	
2. Agree on a work plan and timeline	<ul style="list-style-type: none"><li>● Work backwards from when you need your PN program to be implemented.</li><li>● Be sure to allow time for navigator recruitment, selection, and pre-service training.</li></ul>	

## Suggested Steps in Planning and Initiating a Patient Navigation Program

Step	Components/Factors to Consider	Notes
3. Review PN program requirements and scope	Include: <ul style="list-style-type: none"> <li>• Funder requirements</li> <li>• Organizational preferences</li> </ul>	
4. Explore PN models and determine program scope, components, and strategies	<ul style="list-style-type: none"> <li>• Look at models presented in Chapters 4 and 5 of this guide.</li> <li>• Talk to staff of existing PN programs in your area or nationally.</li> </ul>	
5. Determine remaining information needs/gaps and how to meet them	Arrange to get information: <ul style="list-style-type: none"> <li>• From experts</li> <li>• From stakeholders</li> <li>• Through sources identified in this Guide or on Internet</li> </ul>	
6. Agree on roles for your navigators	<ul style="list-style-type: none"> <li>• Specify their roles.</li> <li>• Identify things they will NOT do.</li> </ul>	
7. Research and ensure ability to meet legal or regulatory requirements	Include: <ul style="list-style-type: none"> <li>• Background checks for navigators</li> <li>• CHW certification/credentialing/regulations</li> <li>• HIPAA and other privacy or confidentiality requirements</li> <li>• Transportation and insurance</li> </ul>	
8. Agree on PN program structure and supervision	<ul style="list-style-type: none"> <li>• Decide where navigators will “fit” into your project and organizational structure.</li> <li>• Decide who will supervise your navigators.</li> <li>• Agree on ways to ensure support and guidance from clinicians.</li> </ul>	
9. Address Human Resources issues	<ul style="list-style-type: none"> <li>• Consider navigator salaries and benefits.</li> <li>• Determine qualifications and preferences.</li> <li>• Develop a plan for recruitment and selection.</li> <li>• Prepare a Position Announcement.</li> </ul>	
10. Agree on training and career development needs and sources to prepare your staff to work effectively with navigators	Agree on: <ul style="list-style-type: none"> <li>• Training that must be completed before navigators begin serving clients</li> <li>• Additional training to be completed after services begin</li> <li>• Use of clinical support/case reviews</li> <li>• Opportunities to learn from other navigators</li> </ul>	
11. Agree on and establish partnerships and referral	<ul style="list-style-type: none"> <li>• If you are a medical provider, includes relationships with support service providers.</li> <li>• If you are a non-medical provider, includes relationships with both medical, other clinical, and</li> </ul>	

## Suggested Steps in Planning and Initiating a Patient Navigation Program

Step	Components/Factors to Consider	Notes
relationships	support service organizations.	
12. Develop protocols and other materials to guide navigators	Include: <ul style="list-style-type: none"> <li>• Methods to be used in documenting services provided and client barriers and needs</li> <li>• Work with multidisciplinary teams within your organization and with key partners</li> <li>• Outline of how newly diagnosed HIV-positive individuals and high-risk HIV-negative individuals are to be identified and assigned to navigators</li> <li>• Outline of how individuals who are out of care are to be identified</li> <li>• Development of needed client and navigator forms</li> </ul>	
13. Complete PN program design and description	<ul style="list-style-type: none"> <li>• Documentation of decisions about scope, structure, and components</li> <li>• Summary of protocols and materials</li> </ul>	
14. Seek and use feedback on program plan from key internal & external stakeholders	<ul style="list-style-type: none"> <li>• Perspectives on model and approach</li> <li>• Willingness to cooperate with implementation efforts</li> </ul>	
15. Recruit and select navigators	Includes: <ul style="list-style-type: none"> <li>• Use of various methods of recruitment (word of mouth, outreach to partners, use of social media, use of traditional media)</li> <li>• Consistent review of applicants using a defined process and tools</li> <li>• Checking of references</li> <li>• Hiring</li> <li>• Background checks</li> </ul>	
16. Train newly hired navigators	<ul style="list-style-type: none"> <li>• Use of various training entities and methods</li> <li>• Collaborative training with other organizations where feasible and appropriate</li> </ul>	
17. Begin PN program implementation	<ul style="list-style-type: none"> <li>• Preparations with partners</li> <li>• Identification and selection of clients</li> <li>• First clients assigned to navigators</li> </ul>	
18. Carry out “design evaluation” and regularly assess program status	<ul style="list-style-type: none"> <li>• Review to ensure that PN program is being implemented as planned</li> <li>• Engagement of project team in regular program reviews</li> </ul>	
19. Refine PN model or components as needed	<ul style="list-style-type: none"> <li>• Planning team or senior staff agreement on changes needed</li> <li>• Revisions to protocols</li> <li>• Training of navigators on changes made</li> </ul>	



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## CHAPTER 7: CONCLUSION

### Objectives:

1. To provide a quick summary of the guide
2. To identify key takeaways
3. To suggest action items for organizations developing or refining their patient navigation programs

### Summary

This guide is designed to support high-impact prevention programs in developing PN programs to serve HIV-positive and high-risk HIV-negative individuals. It provides background information on the evolution of patient navigation and its potential benefits, profiles five successful PN projects, identifies factors that contribute to program success as well as challenge and pitfalls, and offers advice on designing and implementing a PN program as an integral part of your prevention program.

Patient navigation is an increasingly popular and valued strategy for supporting and assisting people to obtain testing and diagnosis, navigate the health care and social services system, and identify and address barriers that might otherwise prevent them from accessing services, adhering to treatment plans, remaining in care, and managing their illness. As explained early in the guide, the model was first used in 1990 at Harlem Hospital Center in New York to improve diagnosis, provide for prompt treatment, and increase survival rates for low-income, mostly African American and Latina women with breast cancer. Today, navigators—often peers or other individuals who understand their communities and the local health and human services system—assist in disease prevention, diagnosis, and treatment. Researchers have demonstrated their value in helping people manage many types of cancer, diabetes, high blood pressure, asthma, chronic kidney disease, cardiovascular disease, prenatal care, smoking cessation, child and adult immunizations, and mental health including depression—and HIV.

The guide's profiled navigation programs target MSM, women of color and their families, African Americans and Latinos, and sometimes anyone newly diagnosed or identified as high-risk for HIV. They provide a variety of patient-centered, culturally appropriate services. The profile charts provide specific, practical information on PN models that can help your organization develop an effective PN program.

**Key Takeaways:** Among the most important concepts, hints, and guidance provided for use by high-risk HIV prevention programs are the following:

- HIV-focused patient navigators vary in their roles, but most are engaged in at least two major activities: helping their clients access needed services (prevention, medical care, other clinical services, and social services, including transportation and child care), and working with them to identify and address barriers that might otherwise prevent them from entering or remaining in care or following their treatment plans. Many also do community outreach, implement prevention interventions, help with treatment

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adherence, and develop and maintain relationships with a wide range of service providers—among other tasks.

- Community navigators can bring in-depth knowledge of the target community, both geographical and demographic. Often they are HIV-positive peers who have faced many of the same disease-related challenges and decisions as their clients. Some are HIV-negative but from the community, and share many of the life experiences of their clients, such as substance use, mental illness, unstable housing, and incarceration. These shared experiences help them gain client trust and serve as role models, demonstrating that it is possible to overcome barriers and manage their disease.
- Navigators are most effective when they work as trusted members of an HIV interdisciplinary team, sharing information and insights based on their work with clients, supporting clinical staff, and often serving as the bridge between the client and service providers.
- Client-centered services are a central expectation in navigation; successful programs often train their navigators to use learned skills like Motivational Interviewing to implement that concept.
- Many community navigators can be described as community health workers with the specific knowledge and skills needed for a set of specific roles. Some projects describe navigation as a senior CHW position requiring prior experience as well as training.
- Developing a PN program requires attention to many factors, including clearly defining your navigators' roles; defining job qualifications including knowledge, experience, and personal characteristics; and carefully selecting navigators and then providing appropriate training, supervision, support, and career development. Legal and regulatory issues—from background checks to auto insurance—also need attention.

### **Suggested Actions:**

1. Review carefully the charts in Chapter 5 that profile a diverse group of effective navigator models and their identified success factors and challenges, and follow some of the Internet links to other guides and program reports.
2. Reach out to other programs that have experience with navigator programs for advice.
3. Think carefully about program scope and what your navigators will do—and not do. Your program needs to meet the requirements of PS15-1502 and CDC's expectations and to be appropriate for your organization and its target population(s).
4. Work with other staff and partner organizations to put together a pre-service and in-service training plan that ensures the knowledge and skills needed to fulfill your identified roles. It is likely to include a combination of external and internal training opportunities.

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5. Plan and implement your PN program as an integral part of your HIV high-risk prevention program by engaging other program staff in its development and creating a mutually supportive project team. Consult early and often with clinical staff to help ensure that your navigators are viewed as a resource, not an annoyance.
  6. Build in early assessment to ensure that your navigation program is being implemented as designed (what one profiled program calls “Fidelity Monitoring”) and progressing towards its performance and outcome objectives. Use what you learn for continuous program improvement.

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