

# Advancing the Field of Cancer Patient Navigation: A Toolkit for Comprehensive Cancer Control Professionals



January 2016



Cancer Center

GW Cancer Institute  
THE GEORGE WASHINGTON UNIVERSITY

GW Cancer Institute  
**CANCER CONTROL TAP**  
*Tap into resources to control cancer*

## INTRODUCTION

Welcome to *Advancing the Field of Cancer Patient Navigation: A Toolkit for Comprehensive Cancer Control Professionals*. We developed this toolkit to guide states in advancing patient navigation. Although there are several types of navigators for which the information presented may be relevant, the focus of the toolkit is largely on patient navigators. Throughout this toolkit, we use the term “patient navigators” to specifically refer to navigators who are neither nurses nor social workers who work within the health care system and we use the term “navigators” broadly to encompass patient navigators, social workers and nurse navigators.

## HOW TO USE THIS TOOLKIT

Use this resource to:

- Educate and train patient navigators
- Provide technical assistance to members of your coalition
- Build navigation networks at the state level
- Identify policy approaches to sustain patient navigation

If you need technical assistance or would like more information, please contact us at [cancercontrol@gwu.edu](mailto:cancercontrol@gwu.edu)

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## ABOUT THE GW CANCER INSTITUTE

The GW Cancer Institute's mission is to foster healthy communities, prepared patients, responsive health care professionals and supportive health care systems through applied cancer research, education, advocacy and translation of evidence to practice. Our vision is a cancer-free world and health care that is patient-centered, accessible and equitable.

The GW Cancer Institute has deep roots in the Washington, DC community and sets standards for patient-centered care nationally. The GW Cancer Institute is also actively involved in cancer control, patient-centered outcomes and health policy research nationally.

## ABOUT THE COMPREHENSIVE CANCER CONTROL PROJECT

In 2013, the GW Cancer Institute was awarded a five-year cooperative agreement to work with the Centers for Disease Control and Prevention (CDC) to design and implement comprehensive, high-quality training and technical assistance to Comprehensive Cancer Control (CCC) programs and their partners to implement cancer control activities. To learn more, visit [www.CancerControlTAP.org](http://www.CancerControlTAP.org).

## DISCLAIMER

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# Advancing the Field of Cancer Patient Navigation: A Toolkit for Comprehensive Cancer Control Professionals

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## SECTION 1: OVERVIEW OF PATIENT NAVIGATION

### History and Background

Patient navigation is an intervention that addresses barriers to quality standard care by providing individualized assistance to patients, survivors and families. The need for patient navigation arose from the understanding that some cancer patients have challenges accessing care. These challenges are often the result of social determinants of health and health disparities.

According to the U.S. Department of Health and Human Services (HHS), “social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship and age that affect a wide range of health, functioning and quality-of-life outcomes and risks” (HHS, n.d.). As shown in Figure 1A, five key factors have been identified that can impact a person’s health.

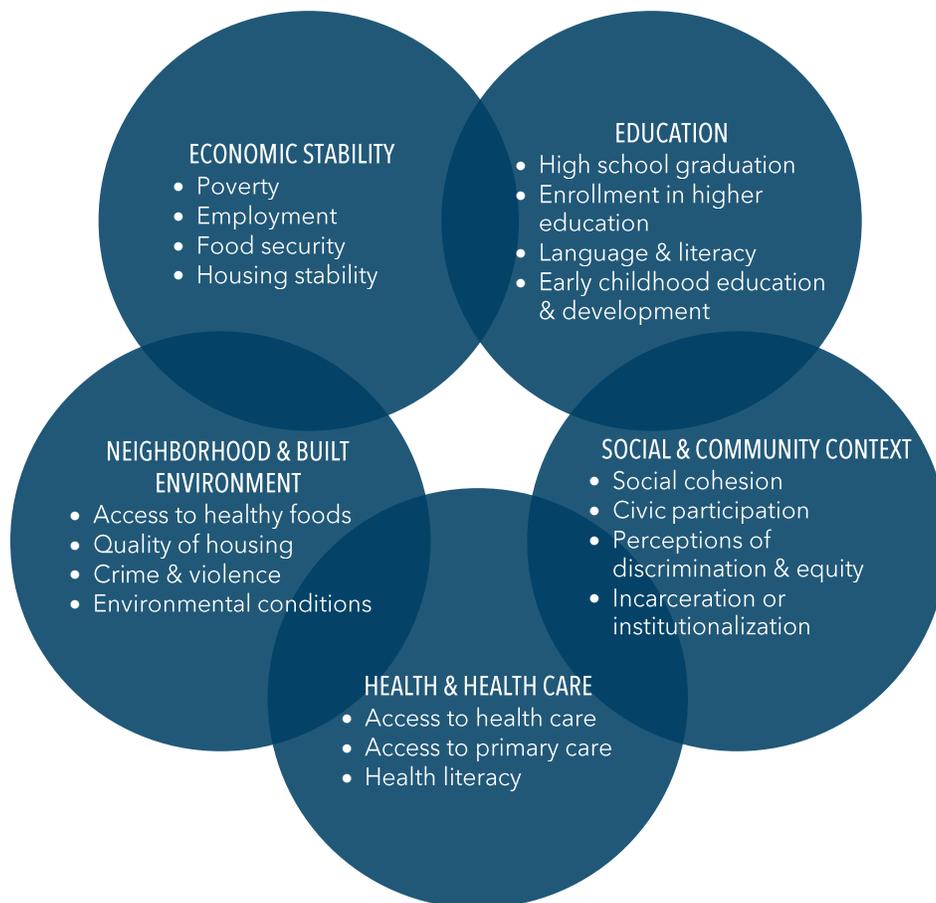


Figure 1A: Social Determinants of Health (Source: HHS, n.d.)

These issues combine to impact health and can make achieving and maintaining positive health outcomes challenging for many people. They can also lead to health disparities. Cancer health disparities are “adverse differences in cancer incidence (new cases), cancer prevalence (all existing cases), morbidity (cancer-related health complications), cancer mortality (deaths), cancer survivorship and burden of cancer or related health conditions that

exist among specific population groups in the United States (National Cancer Institute, 2015). The National Cancer Institute (2008) found that health disparities can be caused by factors such as:

- Barriers to early detection and screening
- Socioeconomic status
- Lack of medical coverage
- Stigma

The first patient navigation program was started in 1990 by Harold P. Freeman in Harlem, New York. Dr. Freeman is a surgeon who began looking at what factors impacted the survival rates of breast cancer patients he was seeing. Most of his patients were African American and were of low economic status (Freeman & Rodriguez, 2011). Half of them did not have insurance at their first visit. Dr. Freeman realized that the five-year survival rate for these women was only 39%, and nearly half of them came to him with disease progression already in stage three or four. Compared with the outcomes of other patients nationally, his patients fared much worse and were coming to see him when the cancer had already progressed to a late stage. Dr. Freeman's actions came from a series of hearings he commissioned as President of the American Cancer Society, resulting in a *Report to the Nation on Cancer in the Poor* that discussed the barriers faced by individuals living in poverty who were impacted by cancer (Ralph Lauren Center for Cancer Care and Prevention, n.d.).

To address health disparities among his patients, Dr. Freeman decided to do two things: 1) he provided free and low-cost exams and mammograms and 2) he hired patient navigators to help remove barriers to timely care (Freeman & Rodriguez, 2011). He found that many patients' treatment was delayed because of financial barriers, such as lack of health insurance; communication and information barriers; medical system barriers; and fear, distrust and emotional barriers. After Dr. Freeman offered accessible screenings and incorporated patient navigators into his practice, the five-year survival rate went from 39% to 70% and late-stage disease dropped from around 50% to 20%. These were great improvements for patients who had experienced significant health disparities (Freeman & Rodriguez, 2011).

Today, many navigation programs exist across the country. The intervention has expanded across the cancer continuum (from screening to diagnosis, treatment, survivorship and end of life care) and has been replicated in other disease areas, such as cardiac care and diabetes. The American College of Surgeons Commission on Cancer, which accredits cancer programs, now requires cancer programs to have a navigation process to maintain accreditation (Commission on Cancer, 2012). This new standard has led to an increase in the number of cancer navigation programs nationwide.

Navigation programs vary across organizations and generally differ by the type of organization that employs the navigator, the number of navigators employed, the point in the continuum of care that the navigator focuses on, the cancer type the navigator focuses on and the characteristics of the patients the navigator supports (see Figure 1B). Many navigators are either part of a cancer program, meaning a hospital or clinic, or part of a community-based organization. Some navigators, like those employed by the American Cancer Society, are a hybrid. These navigators are American Cancer Society employees and provide American Cancer Society resources to patients *and* they are physically situated in a cancer program setting.

TYPE OF ORGANIZATION	NUMBER OF NAVIGATORS	CONTINUUM OF CARE	CANCER TYPE	PATIENT TYPE
<ul style="list-style-type: none"> <li>• Cancer program</li> <li>• Community organization</li> <li>• Hybrid</li> </ul>	<ul style="list-style-type: none"> <li>• One</li> <li>• More than one</li> </ul>	<ul style="list-style-type: none"> <li>• Across the continuum of care</li> <li>• Points in continuum of care (screening, treatment, survivorship, recurrence, end of life)</li> </ul>	<ul style="list-style-type: none"> <li>• One/a few</li> <li>• Many/any type</li> </ul>	<ul style="list-style-type: none"> <li>• All patients</li> <li>• High-need patients</li> </ul>

Figure 1B: Patient Navigation Program Differences

Some programs have a single navigator, while other programs have two or more who may work in different clinics and across different points in the care continuum. Programs could be structured so that a patient navigator follows patients across the continuum of care. In this case, a patient navigator might see a patient who comes in for a screening exam and follow that patient through treatment and beyond.

Other patient navigation programs have navigators at one or more points in the continuum. In this case, a navigator would see patients in the screening segment of care and then either help the patient get to treatment or “hand off” the patient to a different navigator who works with patients in treatment. Navigation programs may also be focused on patients with a particular type of cancer or a few types of cancer, or they may focus on patients with any cancer type. Finally, some navigation programs see all patients while others may focus specifically on high-need patients, such as those living with multiple co-morbidities, living in poverty or with low health literacy.



## Navigator Roles

Navigators may have different education and training backgrounds (Willis et al., 2013). Some navigators have clinical licenses, such as nurses and social workers, while other navigators are professionals who do not have a clinical license. Navigators may also be peers. Table 1A illustrates the types of navigators and their areas of focus.

Table 1A: Types of Navigators and Areas of Focus

Type of Navigator	Professional Summary
<p><i>Nurse Navigators</i></p> <ul style="list-style-type: none"> <li>• Hold a clinical license</li> <li>• Unique focus on clinical decision-making, symptom management and care coordination</li> <li>• Unique understanding of oncology, medical and health information</li> </ul>	<p>Nurse navigators are professional nurses trained to specialize in working with oncology patients. This requires a nursing degree and a clinical license. Nurse navigators focus primarily on the patient's clinical needs and care coordination, and have advanced understanding of medical, oncology and health information. Nurse navigators refer patients to social workers for psychosocial and/or social service needs as well as patient navigators or peer navigators to address non-clinical barriers.</p>
<p><i>Social Workers</i></p> <ul style="list-style-type: none"> <li>• Hold a clinical license</li> <li>• Unique focus on psychosocial support, counseling and social services</li> <li>• Unique understanding of psychosocial information and social service resources</li> </ul>	<p>Social workers are trained to work with oncology patients. This requires a Master's Degree in Social Work and a clinical license. In addition to addressing barriers facing patients, social workers also have advanced understanding of psychosocial issues including appropriate mental and behavioral health interventions. They are also fluent in available social service resources and assist patients in obtaining the resources and services they need to address their concerns. Social workers refer to nurse navigators for clinical concerns as well as patient navigators or peer navigators to address non-clinical barriers.</p>
<p><i>Patient Navigators</i></p> <ul style="list-style-type: none"> <li>• Do not hold a clinical license</li> <li>• Unique focus on helping to address practical barriers for patients</li> <li>• Unique understanding of resources available to solve non-clinical barriers</li> </ul>	<p>Patient navigators come from a variety of professional backgrounds. They specialize in addressing non-clinical barriers facing patients such as:</p> <ul style="list-style-type: none"> <li>• Logistical issues</li> <li>• Insurance and financial challenges</li> <li>• Education and employment issues</li> <li>• Communication challenges</li> <li>• Cultural, religious or spiritual concerns</li> </ul> <p>Patient navigators adhere to strict boundaries and refer to nurse navigators for medical concerns and treatment decision assistance and to social workers for patients' psychosocial care needs</p>
<p><i>Peer Navigators</i></p> <ul style="list-style-type: none"> <li>• Do not hold a clinical license</li> <li>• Volunteers who focus on non-clinical challenges facing patients</li> </ul>	<p>Peer navigators are volunteers and are often cancer survivors and/or live in the communities they serve. They have a unique understanding of the challenges facing the patients they serve. Peer navigators must adhere to strict boundaries referring to nurse navigators for clinical needs, social workers for psychosocial and social service needs and patient navigators for additional assistance with practical challenges.</p>

Navigators may also play roles similar to community health workers (CHWs) (Willis et al., 2013). Often CHWs are from the same communities as the people they work with and focus on disease prevention and wellness. Cancer patient navigators, on the other hand, focus on a single disease and help patients access and get through treatment. These terms are not always fully distinguished, so sometimes the terms "patient navigator" and "CHW" are used interchangeably.

Because the profession of navigation is new and growing quickly, there may be confusion about roles of different types of navigators. In 2013, the Oncology Nursing Society released its [Oncology Nurse Navigator Core Competencies](#) to describe Oncology Nurse Navigators' required fundamental knowledge and skills. In 2015, the GW Cancer Institute released [Core Competencies for Non-Clinically Licensed Patient Navigators](#) to clarify the role of patient navigators who do not hold a clinical license (see Appendix A for competencies and Appendix B for a sample patient navigator job description). Although core competencies for social workers who serve as patient navigators do not exist, many duties are part of social workers' general scope of practice, and the Association of Oncology Social Work has defined a specific [Scope of Practice in Oncology Social Work](#).

Patient navigators serve an important function on the health care team. As Figure 1C illustrates, patient navigators work closely with nurses, social workers, physicians and other members of the team. They help to support these roles by freeing up team members to operate at the top of their licenses. If a patient navigator can address practical issues a patient may be dealing with, then the social worker can focus on psychosocial concerns, the nurse can focus on clinical care coordination and decision-making and the physician can focus on delivering the appropriate treatment.

Patient navigators are key members of the multidisciplinary care team. Not only do navigators work within their home health system, but they are also important contacts for external health care systems, as well as community members, organizations and other stakeholders. Patient navigators can serve as essential advocates for patient care and high functioning health care systems that are responsive to the needs of patients, providers and community members.

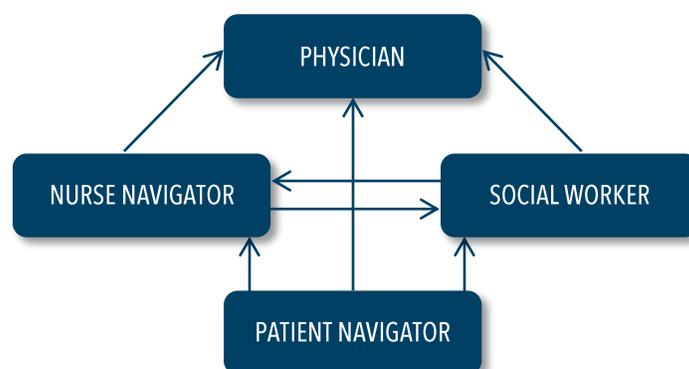


Figure 1C: The Role of Patient Navigators on the Multidisciplinary Team

## Roles of Comprehensive Cancer Control Programs in Promoting Navigation

CCC programs and coalitions have been increasing their focus on patient-centered cancer care to improve cancer outcomes. One reason we created this toolkit is to help CCC professionals think through potential role(s) in improving access to patient-centered care in their state or community. The following are three main strategies that the subsequent chapters will explore in detail:

1. Technical assistance and training
2. System change
3. Policy

## Resources

The following resources provide more information on the background of patient navigation:

- [Standard Occupational Classification System Submission](#): The GW Cancer Institute led a submission to the Standard Occupational Classification System to include patient navigation as a profession in the classification system.
- [Oncology Nursing Society, the Association of Oncology Social Work and the National Association of Social Workers Joint Position on the Role of Oncology Nursing and Oncology Social Work in Patient Navigation](#): In 2010, the Oncology Nursing Society, Association of Oncology Social Workers and National Association of Social Workers released a statement recognizing patient navigation as an essential component of cancer care.
- [Academy of Oncology Nurse and Patient Navigators \(AONN+\)](#) “The mission of AONN+ is to advance the role of patient navigation in cancer care and survivorship care planning by providing a network for collaboration and development of best practices for the improvement of patient access to care, evidence-based cancer treatment and quality of life during and after cancer treatment” (AONN+, n.d.).

### Journal Articles

- Freeman, H.P., Rodriguez, R.L. (2011). History and principles of patient navigation. *Cancer*, 117(15suppl), 3539-3542. <http://dx.doi.org/10.1002/cncr.26262>
- [National Patient Navigation Leadership Summit \(NPNLS\): Measuring the impact and potential of patient navigation](#) (2011). Supplement to *Cancer*.
- Pratt-Chapman, M., Willis, A., Masselink, L. (2014). [Core competencies for non-clinically licensed patient navigators](#). The George Washington University Cancer Institute. Washington, DC.
- Pratt-Chapman, M., Willis, A. (2013). Community cancer center administration and support for navigation services. *Seminars in Oncology Nursing*, 29(2), 141-148. <http://dx.doi.org/10.1016/j.soncn.2013.02.009>
- Willis, A., Pratt-Chapman, M., Reed, E., Hatcher, E. (2014). [Best practices in patient navigation and cancer survivorship: Moving toward quality patient-centered care](#). *Journal of Oncology Navigation and Survivorship*.
- Willis, A., Reed, E., Pratt-Chapman, M., Kapp, H., Hatcher, E., Vaitones, V.... Washington, E. (2013). Development of a framework for patient navigation: Delineating roles across navigator types. *Journal of Oncology Navigation & Survivorship*, 4(6), 20-26.

### Health Disparities Information

- [Intercultural Cancer Council \(ICC\)](#): The ICC offers a series of [Cancer Fact Sheets](#) on a variety of medically underserved populations.

- National Cancer Institute's [Center to Reduce Cancer Health Disparities](#) (CRCHD): CRCHD initiates, integrates and engages in collaborative research studies with NCI divisions and NIH institutes and centers to promote research and training in cancer health disparities and to identify new and innovative scientific opportunities to improve cancer outcomes in communities experiencing an excess burden of cancer.
- Office of Minority Health's [Think Cultural Health](#) website: This site offers the latest resources and tools to promote cultural and linguistic sensitivity in health care as well as free continuing education programs and tools to help organizations provide respectful, understandable and effective services.

## SECTION 2: TRAINING AND TECHNICAL ASSISTANCE

### A. Advancing Patient Navigation Through Training

CCC programs and coalitions have the opportunity to play a significant role in advancing patient navigation through training and technical assistance. Depending on CCC resources, programs and coalitions can promote existing trainings, fund navigator participation in available trainings or coordinate local training; serve as the convener of a state navigation network; and facilitate technical assistance through the network

#### Available Patient Navigation Trainings

Training is critical for making sure patient navigators are prepared to effectively work with patients to address barriers. It also helps create consistency across the profession by making sure patient navigators have similar knowledge and skills. Several national patient navigator training programs exist. Table 2A lists some existing national navigation trainings along with their format, target audience and cost.

Table 2A: National Patient Navigation Trainings

Training	Format	Website	Target Audience	Cost
The GW Cancer Institute's Oncology Patient Navigator Training: The Fundamentals	<ul style="list-style-type: none"> <li>• Online</li> <li>• Self-paced</li> </ul>	<a href="http://tinyurl.com/GWOnlineAcademy">http://tinyurl.com/GWOnlineAcademy</a>	Cancer patient navigators	Free
Patient Navigator Training Collaborative	<ul style="list-style-type: none"> <li>• In-person</li> <li>• Online</li> <li>• Self-paced</li> <li>• Special topic webinars</li> </ul>	<a href="http://patientnavigatortraining.org">http://patientnavigatortraining.org</a>	Patient navigators, social workers, nurses and community health workers	Varies
Harold P. Freeman Patient Navigation Institute	<ul style="list-style-type: none"> <li>• In-person</li> <li>• Online</li> </ul>	<a href="http://www.hpfreemanpni.org">http://www.hpfreemanpni.org</a>	Anyone interested in patient navigation	\$995
Educare Breast Health Navigator Training	<ul style="list-style-type: none"> <li>• In-person</li> </ul>	<a href="http://www.educareinc.com/training_nav.php">http://www.educareinc.com/training_nav.php</a>	Cancer RNs/NPs/PAs	\$2,295
Georgetown University Certificate in Patient Navigation	<ul style="list-style-type: none"> <li>• In-person</li> </ul>	<a href="http://scs.georgetown.edu/programs_nc/CE0120/patient-navigation?dID=39">http://scs.georgetown.edu/programs_nc/CE0120/patient-navigation?dID=39</a>	Anyone interested in navigation	\$2,985
Smith Center Integrative Patient Navigation Training	<ul style="list-style-type: none"> <li>• In-person</li> </ul>	<a href="http://www.smithcenter.org/institute-for-integrative-oncology-navigation/our-training.html">http://www.smithcenter.org/institute-for-integrative-oncology-navigation/our-training.html</a>	Anyone interested in navigation	\$1,200-1,600
Sonoma State University Health Navigator Certificate	<ul style="list-style-type: none"> <li>• In-person</li> <li>• Online</li> </ul>	<a href="http://www.sonoma.edu/exed/health-navigator/">http://www.sonoma.edu/exed/health-navigator/</a>	Anyone interested in navigation	\$4,800
The Graduate Institute Certificate in Integrative Health Coaching and Patient Navigation	<ul style="list-style-type: none"> <li>• In-person</li> </ul>	<a href="http://www.learn.edu/healthcoaching">http://www.learn.edu/healthcoaching</a>	Professionals interested health coaching and navigation	\$5,581

Training can serve as the basis for certification for patient navigators, which elevates the credibility of patient navigators as an integral component of the health care team. CHWs have been successful in creating state-based certification. In 2016, AONN+ is launching a certification program for both nurse navigators and patient navigators.

### **Patient Navigation Training from the GW Cancer Institute**

In 2015, the GW Cancer Institute launched the *Oncology Patient Navigator Training: The Fundamentals*, which is the first free, online competency-based training available nationally for patient navigators. The training is based on a set of competencies developed by the GW Cancer Institute through a collaborative process that included navigators and navigation experts across the country. The full competencies are available in Appendix A and [online](#).

Through a rigorous process, the training curriculum was developed to cover the fundamental knowledge and skills needed by cancer patient navigators. Figure 2A outlines the training curriculum.



Figure 2A: "Oncology Patient Navigator Training: The Fundamentals" Curriculum

## Comprehensive Cancer Control Programs' Role in Enhancing Training

In addition to promoting existing trainings, states can create customized trainings that are responsive to local navigator needs. For example, a state can hold an in-person conference for navigator continuing education. This section discusses strategies for one-time or annual in-person trainings. Section 2B discusses strategies for ongoing patient navigation network meetings. You can plan an in-person training using the following steps:

- Conduct a needs assessment to identify learner needs
- Develop learning objectives tied to learner needs
- Match instructional methods with learner needs
- Create an evaluation plan that aligns with learning objectives

### Conduct a Needs Assessment

A needs assessment will help to make sure training content matches what learners need to know. There are several things that can be done to assess need, such as conducting an informal survey of patient navigators, hosting a focus group with patient navigators, asking leaders in patient navigation about educational needs in the state and talking with employers about what they perceive to be the greatest training needs. We have identified some potential topics that may be of interest to patient navigators

- Patient interaction tips
- Advocacy and self-advocacy
- Bilingual patient navigation, interpretation and cultural humility
- Boundaries, burnout and self-care
- Cancer disease and treatment process
- Collaboration across systems
- Community-clinical linkages
- Creating a state-wide patient navigation infrastructure
- Documentation and tracking tools
- Ethics
- Integrative patient navigation
- Making the case for patient navigation
- Palliation and hospice
- Role comparisons (treatment centers vs. community organizations; nurses and social workers)
- Sharing of resources: What exists and what gaps need to be addressed

### Develop Learning Objectives

Learning objectives clarify what attendees will learn as a result of the session. The Eberly Center for Teaching Excellence at Carnegie Mellon University (n.d.) provides some helpful tips for creating learning objectives:

- *Learning objectives should be learner-centered.* This prompt can help you frame learning objectives and determine what learners should understand and be able to do.
- *Learning objectives should break down the different skills needed for a task.* For example, if you want patient navigators to learn how to assess patients' needs and barriers, you could break that down into several learning objectives: Describe methods for assessing patients' needs and barriers and apply the teach-back method to assess patient needs and barriers.
- *Learning objectives should have action verbs.* Action verbs are helpful for measuring how well learners can do what you expect them to do. The Eberly Center has a [list of action verbs](#) that you can use when creating learning objectives.

- *Learning objectives should be measurable.* Having a measurable learning objective means you should be able to assess whether a learner has gained a particular skill. If you are using action verbs then it will be easier to measure. For example, if you wanted to measure whether a patient can describe methods for assessing patients' needs and barriers, you could have a learner answer a question on a post-test or provide a verbal response to a trainer.

### Match Instructional Methods with Learner Needs

The following instructional methods in Figure 2B have been adapted from the Eberly Center.

LECTURES	PANEL PRESENTATIONS	SMALL CASE STUDY GROUP DISCUSSIONS	ROLE PLAYING
<ul style="list-style-type: none"> <li>• Speakers with expertise on a topic present content to learners</li> </ul>	<ul style="list-style-type: none"> <li>• A group of two to five speakers present shorter presentations on a related topic</li> </ul>	<ul style="list-style-type: none"> <li>• Group members discuss scenarios to help them apply skills, develop collaborative skills and relate knowledge to the real world. See Appendix C for sample case studies and discussion quotes.</li> </ul>	<ul style="list-style-type: none"> <li>• Learners act out scenarios and receive feedback from others. See Appendix C for sample case studies and role play guidance.</li> </ul>

Figure 2B: Instructional Methods and Examples

Assessment is another important component that should be incorporated into training efforts. There are several types of assessments including (Berthold & DeCarlo, 2014):

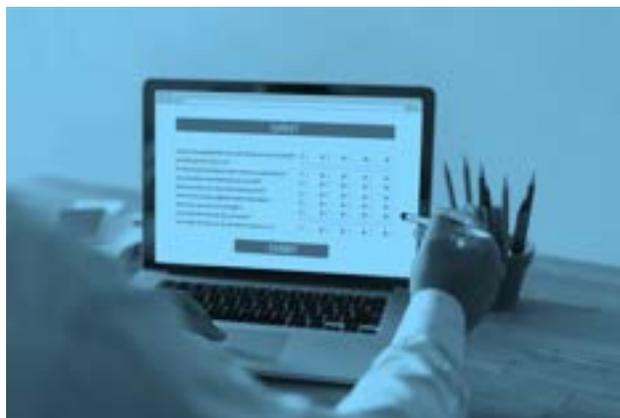
- *Self-Assessment.* Learners should be given opportunities to assess their own learning through state training and education. Self-assessments could occur in the form of written assignments that allow learners to reflect on content or verbal assessments during training. A sample self-assessment tool based on the Core Competencies for Oncology Patient Navigators is available in Appendix E.
- *Peer Assessment.* Providing constructive feedback to others is also important for trainees. Peer assessment could be included in trainings through small group discussions or role playing activities.
- *Assessment by Trainers.* Trainers can provide valuable written or oral feedback for learners. Time can be included in training for trainers to provide feedback to individuals or groups of learners, such as through role-playing exercises.
- *Assessment by Internship.* Internships are opportunities for new patient navigators to receive more hands-on training. States can consider working with local agencies to create internship opportunities for patient navigators.

## Create an Evaluation Plan that Aligns with Learning Objectives

Evaluation is critical for making sure the training meets learner needs and that the learning objectives were achieved. Questionnaires are often used to assess participant satisfaction, self-rated knowledge change and content knowledge.

### *Assess Satisfaction*

You can assess participant satisfaction through a questionnaire offered at the end of the training. This information can help you improve the training if you offer it again or help you prove to funders that it was successful. For example, you could ask participants to rate their level of agreement with the following statements. You can use a 5-point Likert scale that includes Strongly Agree, Agree, Neutral, Disagree and Strongly Disagree.



- I am likely to refer back to the training materials to inform my navigation efforts.
- I would recommend the training to my colleagues.
- I will use what I learned in my current or future job.
- I am better prepared to navigate patients.
- The information provided in this training was clear.
- There was enough time for discussion.
- The presenter(s) used examples that were helpful.
- The presenter(s) responded well to questions during the program.
- The presenter(s) recognized that the audience can help teach one another.
- Communications regarding the training were clear.
- The training was valuable for me to attend professionally.
- The training was well organized and ran smoothly.
- The length of the training was appropriate.
- Overall, the training was worthwhile.

You may also want some open-ended questions, such as:

- What is the most beneficial thing you learned in this training?
- How could this training be better? What could be changed to improve the training? (e.g., instructor, information you wanted to learn)
- What were you hoping to learn about that wasn't covered?
- Is there anything else about this training you would like to tell us about?

### *Measure Self-Rated Knowledge Change*

One way to measure knowledge change is using a pre- and post-test. Before the meeting starts, participants complete a survey where they rate their level of knowledge on a topic. These statements should be tied to your learning objectives. For example, if a learning objective is to "describe methods for assessing patients' needs and barriers," then you would ask participants to rate their level of agreement with the statement "I am able to describe methods for assessing patients' needs and barriers." You would then ask this question again

in a post-test immediately after the meeting. You can compare the pre-test responses with the post-test responses to see if knowledge changed.

### Evaluate Content Knowledge

You might also want to assess whether participants learned specific content presented. You can add questions to your post-test to see if participants understood the content. These questions are more likely to be multiple choice questions and should be tied to the learning objectives. Table 2B provides examples of how to evaluate the training.

Table 2B: Example Evaluation Questions by Evaluation Construct

Learning Objective	Satisfaction	Self-Rated Knowledge	Content Knowledge
<i>Describe methods and tools for assessing patients' needs and barriers</i>	<i>Post-test question using 5-point Likert scale: This training adequately described methods and tools for assessing patients' needs and barriers.</i>	<i>Pre- and post-test question using 5-point Likert scale: I am able to describe methods and tools for assessing patients' needs and barriers.</i>	<i>Post-test question, multiple choice: Which of the following is a tool that can be used to assess patients' needs and barriers? a. Myers' Method b. Distress Thermometer c. Patient engagement d. Teach back</i>
<i>Describe the scope of work for patient navigators</i>	<i>Post-test question using 5-point Likert scale: This training adequately described the scope of work for patient navigators.</i>	<i>Pre- and post-test question using 5-point Likert scale: I am able to describe the scope of work for patient navigators.</i>	<i>Post-test question, multiple choice: Which activity is most appropriate for patient navigators? a. Providing clinical education to patients b. Assessing how much information a patient does or does not want to know about his or her illness c. Counseling patients experiencing distress d. Making referrals for clinical services</i>

## B. Providing Technical Assistance to Navigators through Navigation Networks

### Benefits of a State Navigation Network

Navigators have complex jobs, balancing multiple demands from both patients and the health care team in an environment that can often be stressful and hectic. It is important for navigators to have a network of peers to work with and rely upon when questions, concerns, and challenges arise. Navigator networks can serve multiple purposes including providing a space for networking among colleagues, promoting mentorship opportunities, allowing for feedback regarding professional concerns, encouraging continuing education through guest speakers or activities, and creating a united group of navigators who can address health care challenges at micro, mezzo, and macro levels within an entire community.

## State Navigation Networks

Below is a list of state navigation networks and contacts for them. If your state does not have a network, you may want to consider working with [a chapter of the Academy of Oncology Nurse and Patient Navigators \(AONN+\)](#) in your state. For example, the Indiana and Texas CCC Programs have connected with AONN+ chapters to collaborate. If your state network is missing from this list, please contact us at [cancercontrol@gwu.edu](mailto:cancercontrol@gwu.edu).

Table 2C: State Navigation Networks and Contacts

Network	Contact	Email
<a href="#">Cancer Patient Navigators of Georgia</a>	Angie Patterson	<a href="mailto:apatterson@georgiacore.org">apatterson@georgiacore.org</a>
<a href="#">Colorado Patient Navigator and Community Health Worker Collaborative</a>	Andrea (Andi) Dwyer	<a href="mailto:andrea.dwyer@ucdenver.edu">andrea.dwyer@ucdenver.edu</a>
<a href="#">DC Metro Patient Navigation Network</a>	Elizabeth Hoffler	<a href="mailto:navigation@gwu.edu">navigation@gwu.edu</a>
<a href="#">Deep South Navigation Network</a>	Mark A. Wiersma	<a href="mailto:mwiersma@uabmc.edu">mwiersma@uabmc.edu</a>
<a href="#">Florida Community Health Worker Coalition</a>	Marion Banzhaf	<a href="mailto:Marion_Banzhaf@doh.state.fl.us">Marion_Banzhaf@doh.state.fl.us</a>
<a href="#">'Imi Hale Native Hawaiian Cancer Awareness Network</a>	Amanda Allison; Kathryn Braun	<a href="mailto:hookele@papaolalokahi.org">hookele@papaolalokahi.org</a> ; <a href="mailto:kbraun@hawaii.edu">kbraun@hawaii.edu</a>
<a href="#">Kentucky Cancer Patient Navigation Network</a>	Katie Bathje	<a href="mailto:kbathje@kycancerc.org">kbathje@kycancerc.org</a>
<a href="#">Maryland Patient Navigation Network</a>	Thuy Nguyen	<a href="mailto:thuy.nguyen@maryland.gov">thuy.nguyen@maryland.gov</a>
<a href="#">Midwest Cancer Alliance Navigator Network</a>	Carol Bush	<a href="mailto:cbush@kumc.edu">cbush@kumc.edu</a>
<a href="#">Mountains of Hope Cancer Coalition (WV)</a>	James Keresztury	<a href="mailto:jkeresztury@hsc.wvu.edu">jkeresztury@hsc.wvu.edu</a>
<a href="#">New Mexico Patient Navigation Network</a>	Elba Saavedra	<a href="mailto:elsaave@unm.edu">elsaave@unm.edu</a>
<a href="#">New York Colonoscopy Patient Navigation Program</a>	Sonia Viellgas	<a href="mailto:svillega@health.nyc.gov">svillega@health.nyc.gov</a>
<a href="#">Northeast Ohio Patient Navigation Collaborative Navigator Network</a>	Ginny Pate	<a href="mailto:ginny@carmellarose.org">ginny@carmellarose.org</a>
<a href="#">Pennsylvania Patient Navigator Network</a>	Karen Schaderer	<a href="mailto:kschwade@wpahs.org">kschwade@wpahs.org</a>
<a href="#">Virginia Cancer Patient Navigation Network</a>	Cristi Sheffield	<a href="mailto:CWS9Q@hscmail.mcc.virginia.edu">CWS9Q@hscmail.mcc.virginia.edu</a>

Below are some questions you might ask as you develop and improve your Navigation Network:

### Network Coordination

- Will your network be coordinated by an organization like a health foundation, a cancer center or a state department of health or by an individual?
- What coordinating activities will be required? Possible activities might include:
  - Coordinating meetings
  - Coordinating membership/ membership database
  - Coordinating communications

- Will you have committees and/or subcommittees? What will they be tasked with doing? Examples of duties might include:
  - Establishing navigation goals
  - Strategizing grant funding opportunities
  - Promoting competency-development of network members
- How will decisions be made?
- How will you communicate with members? Possibilities might include:
  - Maintaining a website or using social media
  - Sending monthly newsletters
  - Organizing a conference, trainings or live meetings
  - Live steering meetings or phone calls
  - Emails to members
- What resources do you have for your network? How will you fund network activities? Possible funding might come from:
  - Foundations
  - Cancer centers
  - Departments of health
  - Pharmaceutical companies
  - State budgets
  - Membership fees

## Membership

- Who will be eligible for membership? All navigator types? Only certain navigators?
- How will you support your members? You might consider providing:
  - Resources and opportunities
  - Data tracking software
  - Resource manuals
  - Clinical pathway guidelines
  - Networking opportunities
  - Relationships with influential organizations
  - Training opportunities
  - Connections with other navigators
  - Helpful websites
  - A map/directory of the patient navigators in each region of the state

## Network Mission

- Will you have a mission statement? If so, who will craft it?
- What are your goals for the future? Ideas might be to:
  - Conduct a needs assessment
  - Implement more training opportunities
  - Improve quality of trainings
  - Apply for funding to advance network goals
  - Apply for 501(c)(3) status
  - Increase membership
  - Advocate for the importance of navigation in your state

## Professional Development

- How will you support professional development of your members? Possibilities might include:
  - Annual conferences
  - Professional seminars
  - Webinars
  - Special interest groups
  - Networking opportunities

## Evaluation

- How will you know if you are successful? You might consider:
  - A database that captures patient information like cancer type, treatment modalities, demographics, services performed and navigation interactions
  - Performance evaluations for navigators
  - Training surveys

## Tips for State Navigation Networks

States play a key role in professional development for navigators. Professional development opportunities specific to patient navigation should:

- Be competency-based and focus on core skills
- Include continuing education to support knowledge development and skill building
- Include supervisor training along with direct practice navigation training



Many navigation networks meet multiple times per year. This section provides some tips for those meetings, which may be in conjunction with or separate from in-person training that we discussed in Section Two.

### Group Considerations

When creating a patient navigator group, keep in mind the following issues:

- *What's in it for them?* Patient navigators want to work with patients, and time away from their responsibilities may be a challenge or even an unwelcome distraction. Remember that this cannot just be another meeting – the navigators must gain something valuable from their time.
- *What are the personal and professional goals of the participants?* Spend some time working to understand what the navigators hope to accomplish through their participation in the group as well as in their professional role and in their personal lives. Determine how you (and the other group members) can support the aspirations of each navigator.
- *What is the overall goal of the group?* Work with navigators to define an overall goal with buy-in from members. Examples include: (1) provide a welcoming space for networking and professional feedback; (2) facilitate continuing education to build patient navigation knowledge and skills; and/or (3) create an environment in which patient navigators can role play and discuss case studies and other skill-building activities.
- *What are the group dynamics?* Will some navigators dominate the group and intimidate others? If so, you may wish to structure your group around guest speakers. Do the navigators feed off one another's energy and thrive from group work? Perhaps activities will be most useful. Create your agenda around what will benefit navigators the most.
- *Will the group be beneficial to all participants?* This is especially important if your group consists of diverse navigator types or beginning, mid-career and experienced navigators. Make sure that content will generally be accessible and interesting to all.
- *Do you have the appropriate resources (time, expertise and money) to facilitate such a group?* It may seem like a simple task but group management and meeting planning and implementation requires time, coordination and organization.
- *How formal will your group be?* It can be a challenge if the group is informal. There will always be details that must be addressed such as coordinating speakers, ordering food or booking a location. Ask navigators to RSVP to the meeting as well.
- *Will you encourage leadership from patient navigators?* If so, what are the positions that need to be filled (chair, secretary, committee leads, etc.)? Sharing authority and work can help with buy-in and commitment from group members.

### Drafting the Meeting Purpose

Think about the following when drafting a meeting purpose:

- *What:* Is this an in-person or virtual (phone or webinar) meeting? Is this a regular meeting or one on a special topic?
- *Who:* Determine if you will invite all or only certain navigator types. Content must be appropriate for all navigators in attendance. Are there other people who should participate, such as supervisors, administrators or patients?

- *When:* It may be helpful to survey navigators to determine which day of the week and time of day typically works best for them as well as how long they would like the meetings to be.
- *Where:* Choose a location that is convenient for navigators to access during their workday. You may want to consider alternate locations.
- *Why:* It is important to know what information navigators find most helpful and how they would like to use network meetings. Network leaders should either be committed to planning and implementing these meetings or should appoint a navigator leader and/or committee to ensure well-run meetings that are timely and useful for all in attendance.

## Preparing for the Navigation Meeting

Keep the following in mind when preparing for the navigation meeting:

- Prepare a draft agenda to circulate before the meeting takes place (see below).
- Set ground rules. These could include:
  - Contribute to a safe and positive space
  - Be open to learning
  - Listen to understand
  - Don't judge
  - Speak honestly
  - Participate fully
  - Ask questions
  - Be brief and meaningful
  - Respect confidentiality and each other
  - Attack problems, not people
  - Stay on topic
  - One person speaks at a time
  - Adhere to time limits
  - Limit technology use – keep cell phone checking to a minimum
- If guest speakers will be joining you, ensure that they have all of the information necessary and send a friendly reminder to them a week prior to the meeting. If they will use printed materials, offer to print and provide copies and/or circulate the materials to attendees before the meeting.
- Determine who will lead and facilitate the meeting. This includes a brief welcome and speaker introduction if necessary. It is challenging for a meeting to run informally.
- Ensure that someone is timing the meeting to maintain the schedule.
- Keep meeting notes to provide reminders and improve future meetings.
- If possible, provide food and beverages for attendees. Keep special food requests in mind.
- Encourage attendees to come to the meeting with questions about the prepared topic.
- Create a parking lot to table off-topic conversations for the end of the meeting.
- The day of the meeting make sure that needed technology and logistics are coordinated and working properly. Don't waste anyone's time.
- Prepare all of the relevant handouts and bring them to the meeting (agenda, discussion materials, case studies, etc.)
- Arrive to the meeting early to greet the navigators and get to know them a bit better.

## Draft Agenda

When drafting a meeting agenda, make sure to include the overall meeting goal as well as a list of participants and their job title, employer, and contact information. It can be helpful to also include session times to make sure the meeting stays on schedule. For example, you could draft an agenda like the one below.

- |      |                              |            |
|------|------------------------------|------------|
| I.   | Introductions and Updates    | 15 minutes |
| II.  | Featured Speaker or Activity | 50 minutes |
| III. | Wrap-up and Discussion       | 25 minutes |

## Potential Meeting Activities

Meeting activities can be helpful for increasing learning. Through group feedback, navigators can discuss challenging cases and receive helpful feedback from their peers. Case studies allow navigators to discuss hypothetical examples with each other (see Appendix C). Appendix F includes sample navigator interview questions that can be included in role play or group discussions to prepare navigators for job interviews. Resource sharing can also be helpful; ask navigators to come to the meeting with a printed list of their go-to resources for patients for discussion. Skill building sessions and/or guest speakers can focus on topics such as:

- Cancer basics
- CPT codes
- Culturally sensitive communication
- Deep dive into specific cancers
- End of life issues
- Ethical issues and concerns
- Health care policy issues
- Legal issues
- Management and leadership
- Managing up – working with physicians
- Medical terminology
- Patient advocacy
- Patient assessment skills
- Patient empowerment and self-management
- Patient health literacy
- Patient self-determination
- Patient spirituality and religion
- Scope of practice and making referrals
- Self-care
- Shared decision making
- Social determinants of health
- Health disparities
- Time management
- Understanding Medicaid
- Understanding Medicare
- Working in a multidisciplinary team
- Working with children
- Working with families
- Working with groups
- Working with vulnerable populations

## Evaluating the Group

Once the navigator group is up and running, it will be important to periodically evaluate the group functioning and processes. Important questions to consider include:

- Is your group aligned with and meeting the overall goals? If not, do the goals need to be adjusted to meet navigator needs?
- Are navigators attending meetings? Are navigators engaged when they attend meetings? Why or why not? Should you adjust your approach accordingly?
- Are meetings running well? Do they start and end on time? Do navigators stay on topic? Are all members participating?
- Is the group dynamic working? Is the meeting tone typically positive? Do certain group members need encouragement to participate more fully? Should others sometimes take a back seat?
- If there are action items for the group, are they being completed in a timely manner?
- Are there new or innovative ways to educate and engage group members?
- What are the strengths and weaknesses of the group? What opportunities exist to improve the group processes and outcomes?
- Is the group necessary and useful for navigators? If not, adjustments should be made with input from the group members.

### *Meeting Evaluation Template*

You can also continually evaluate the meetings through participant feedback. You can modify and use the short template in Figure 2C.

We want to make sure that the navigator group contributes to your professional goals. As such, we value your feedback and ask that you answer the following questions in order to improve our future meetings. Feedback is voluntary.

Name (Optional): \_\_\_\_\_

Date: \_\_\_\_\_ Meeting Topic/Speaker: \_\_\_\_\_

1. Did this meeting support the navigation group goals? Why or why not?
2. Did you find the meeting topic important and useful to your work? Why or why not?
3. What, if anything, from the meeting will you incorporate into your work?
4. How can we strengthen future meetings? Do you have ideas for future meeting topics or activities?
5. Is there any information you feel should have been included but was not?
6. Do you have any suggestions for future meeting topics?
7. Do you have any other feedback for the navigation group?

Figure 2C: Meeting Evaluation Template

### *Network Evaluation*

It is good practice to also periodically evaluate your network to make sure it is meeting its stated goals. There are several ways to conduct the evaluation. For example, you may want to host focus groups with network participants. Appendix G includes an example focus group guide that you can modify and use. You could also send out a survey either on paper or electronically. Appendix H includes an example evaluation survey that you can modify and use.

## Sample State Cancer Plan Patient Navigation Goals

You may want to include a patient navigation goal in your state cancer plan to help ensure coordinated patient navigation efforts. When thinking about goals, it might be helpful to review the GW Cancer Institute’s [State Cancer Plans Priority Alignment Resource Guide & Tool](#) to make sure the goals align with national indicators. It also has tips for creating goals, objectives and strategies. Table 2D demonstrates some sample goals, objectives and strategies that you can use.

Table 2D: Sample State Cancer Patient Navigation Goals, Objectives and Strategies

Goal	Objective	Strategy
Increase early detection and appropriate screening for colorectal cancer.	By 2016, increase from 63% to 75% the percentage of adults aged 50 and older who receive risk-based colorectal cancer screening and follow-up using accepted professional guidelines, as measured by the state Behavioral Risk Factor Surveillance System.	<p>Train patient navigators on screening guidelines and best practices to increase screening.</p> <p>Host an annual meeting of the state Navigation Network to assess progress, network and discuss challenges and solutions.</p>
Provide high-quality cancer care to all people diagnosed with cancer in the state.	By 2017, address at least 15,000 patient barriers to accessing high quality care as measured by navigators participating in the state Navigation Network.	<p>Use The GW Cancer Institute’s free Barriers Assessment Tool to track patient barriers at institutions participating in the state Navigation Network.</p> <p>Assess progress at each monthly Navigation Network meeting.</p>
Improve access to and utilization of cancer screening, diagnosis, treatment and related services.	By 2017, increase the number of cancer programs with patient navigators from 7 to 13.	<p>Conduct value assessment at cancer programs with existing navigation programs.</p> <p>Train six cancer programs on how to create a navigation program.</p>

## Resources

- [Eberly Center for Teaching Excellence at Carnegie Mellon University](#): This website has many free resources for teaching and learning, including information on creating learning objectives, selecting instructional activities and conducting assessments.
- [Academy of Oncology Nurse and Patient Navigators \(AONN+\) Chapters](#): This list includes chapters across the country and information about starting a chapter in your location.
- [GW Cancer Institute Comprehensive Cancer Control \(CCC\) Technical Assistance Portal \(TAP\) Cancer Plan Goal Bank](#): The TAP website includes many resources for CCC professionals, including an easy-to-search bank of state cancer plan goals.

## SECTION 3: SYSTEM CHANGE

CCC programs and coalitions can play a role in changing health care systems to embrace patient navigation. This section details a systematic planning, implementation and evaluation process to help ensure development of sound navigation programs. CCC program or coalition member roles might be to champion these strategies within their own institutions or promote them statewide.

### Patient Navigation Program Planning Overview

The GW Cancer Institute offers the [Executive Training on Navigation and Survivorship](#), a free online training that provides individuals with strategic planning techniques for developing, implementing, evaluating and sustaining patient navigation and clinical survivorship programs. Based on feedback from participants, a [Guide for Program Development](#) was created to provide health care professionals with a step-by-step approach to program development, provide key resources and tools and enable health care professionals to develop a cohesive, institution-specific program plan.

The [Guide for Program Development](#) is based on a cycle shown in Figure 3A, adapted from the CDC's [Framework For Program Evaluation](#), which features four elements of program planning: assessment, planning, implementation and outcomes evaluation. Each of these components is highlighted below and explored in detail in the guide.

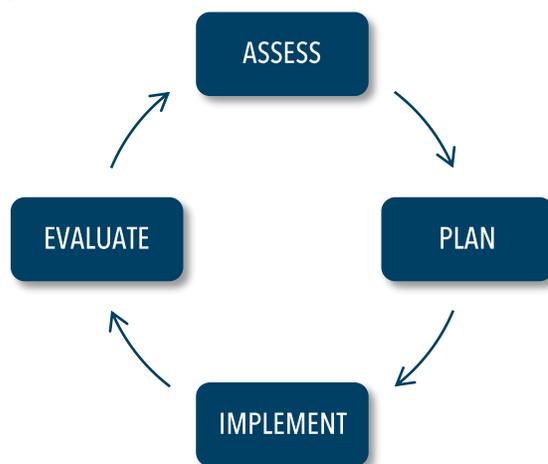


Figure 3A: Program Development Cycle (CDC, 1999)

### ASSESS

#### Conduct a Needs Assessment

A needs assessment is a critical tool for identifying the gap between current and ideal conditions and for identifying barriers and challenges to develop a program responsive to the needs of your patients and your institution's priorities. It will help you assess the needs and beliefs of different stakeholders to inform your program development. When conducting a needs assessment, consider the five needs assessment components described in Figure 3B.

### DEFINING YOUR PATIENT POPULATION

- Enables you to establish an overview of your patient population and some of the key barriers your population faces

### DETERMINING PATIENT FLOW

- Helps you understand how patients move through your institution and at which points they need the most assistance

### INSTITUTIONAL ANALYSIS

- Guides you through understanding your institution's strengths and weaknesses as well as external opportunities and threats (known as a SWOT analysis)

### INTERNAL AND EXTERNAL RESOURCE MAPPING

- Helps you think through existing resources within your institution as well as within your community that may be available to assist your program

### STAKEHOLDER NEEDS ASSESSMENT

- Helps you identify who else could be impacted by your program and what their needs and priorities are

Figure 3B: Needs Assessment Components

To save yourself time and energy, you might review the [community needs assessment](#) required every three years by accredited cancer centers. Annually, the cancer committee reviews and evaluates the navigation process, and new barriers are identified and plans are made to address them.



## PLAN

### Identify Potential Services

There are many services that might be important to your patient population. Some navigation actions that might help your patients include\*:

- Accompany patients to appointments
- Address health literacy challenges
- Assist in appointment scheduling
- Assess family/caregiver needs
- Coordinate care (internal)
- Coordinate care with referring physicians
- Help to recruit patients for clinical trials
- Conduct informational classes†
- Coordinate clinic or multidisciplinary conference
- Conduct distress screenings†
- Assist with employment needs and referrals
- Assist with external/community resource referrals
- Assist with financial assessment and referrals
- Assist with genetic counseling referrals
- Improve timeliness of care
- Assist with insurance coverage issues
- Coordinate language assistance
- Address logistical barriers (e.g., housing utilities, dependent care)
- Assist with nutrition referrals
- Provide patient education†
- Provide or refer for psychosocial support†
- Coordinate transportation assistance
- Coordinate treatment planning†
- Coordinate vocational/career counseling

### Identify Program Goals and Objectives

Your program objectives should be SMART. Whereas a goal is overarching and generally more long-term, an objective is more specific and is generally more short-term than a goal. Figure 3C describes SMART objectives.

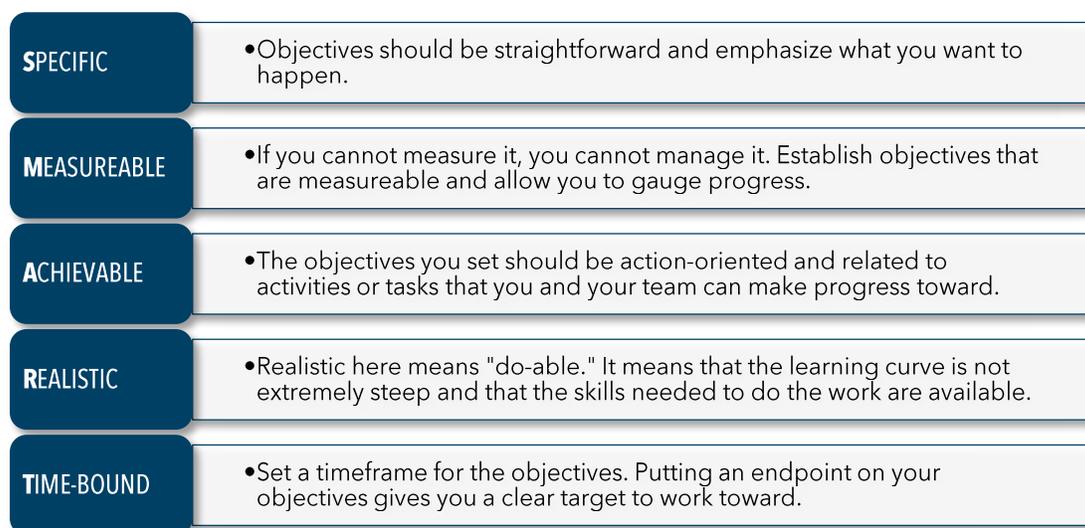


Figure 3C: SMART Objectives (CDC, 2012).

\* Not an exhaustive list of services provided by patient navigators

† As appropriate based on navigator training and type

## Create a Logic Model

A logic model is the “road map” or “blueprint” to document your program plan. The logic model links goals, objectives, activities and inputs, outputs and outcomes. It clarifies what you plan to do, why, how and by when to keep you focused on program goals, track progress and evaluate the program. A logic model includes the four components described in Figure 3D.

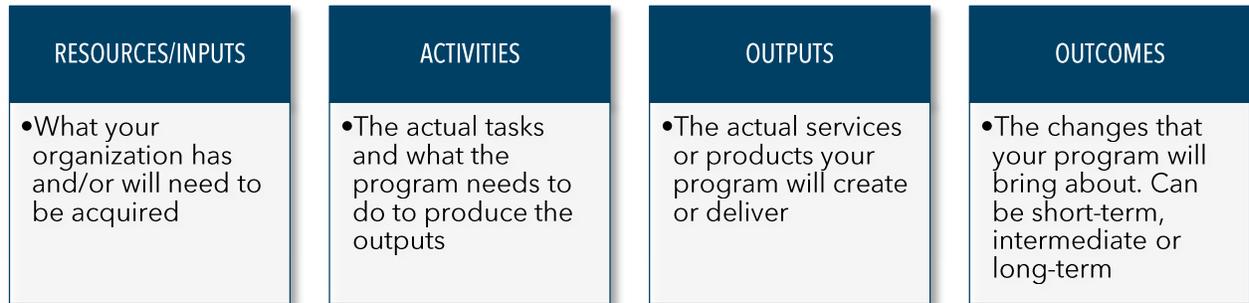


Figure 3D: Logic Model Components

## Develop a Communication Plan

A successful marketing approach can help educate patients and survivors about the services your program offers. It can also help educate providers and staff and give them an opportunity to be involved in the process. A communication plan may help garner public support from influential stakeholders as well. When developing a communication plan think about creating a comprehensive approach that includes multiple stakeholders such as those depicted in Figure 3E.

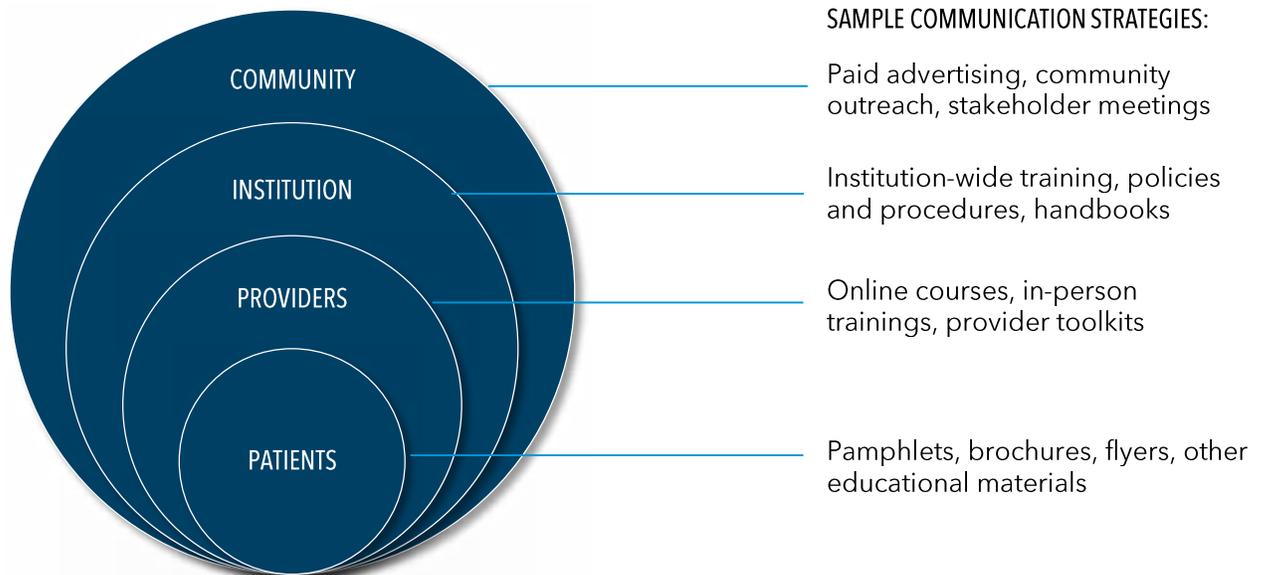


Figure 3E: Multiple Stakeholder Communication

## Create a Budget and Identify Program Funding Options

Many health care professionals cite financial constraints as a significant barrier to program implementation. It is important to think upfront not only about how the program will be initially funded but also how it can be sustainable. Before you can begin to think about funding, you need to identify the anticipated costs involved. Developing a realistic budget will help you determine what resources you need and can afford. Program needs will vary by institution.



Many navigation programs are currently funded by grants, internal funds and leveraging existing resources (The GW Cancer Institute, 2013). Revenue from billable expenses can also be used to support the navigation program. The budget shown in Table 3A below demonstrates some of the costs that may be necessary to launch and maintain a program. For each line item a possible funding source is listed.

Table 3A: Sample Budget

	Cost	Funding Source
<b>Personnel</b>		
Director of Patient Support Services	\$	Internal
Patient Navigator	\$	Internal
Clerical staff	\$	Existing resources
<b>Program Costs</b>		
Facility rental	\$	Existing resources
Facility utilities	\$	Existing resources
Printing & copying	\$	Internal
Patient intake and follow-up tools	\$	No cost/Open source
Marketing materials	\$	Internal
Patient health education seminar	\$	Grant
Conference attendance	\$	Internal
Food for events	\$	Grant
<b>Direct Medical Care</b>		
Referrals, non-subspecialists	\$	Billable
Lab and other tests	\$	Billable

## Identify Evaluation Measures and Procedures

Evaluation is the systematic collection of information about some or all aspects of a program to guide judgments or decisions. Evaluation can be formative, such as needs assessment or process evaluation, or summative, such as outcomes evaluation (CDC, 1999). Formative evaluations help determine need and problems to address. Process evaluations focus on program fidelity by assessing activities that were implemented and the quality, strengths and weaknesses of the implementation. Outcomes evaluation measures the change that your

program will bring about in your target population or social condition. The evaluation plan should build off of your logic model. When choosing measures, select measures that relate to your program and have a purpose in mind. An evaluation plan should include the components outlined in Figure 3F.



Figure 3F: Evaluation Plan Components

## IMPLEMENT

### Implement the Patient Navigation Program

Once you have planned your patient navigation program, you can begin to implement it. This is the action part of the program planning cycle. Since implementation will be based on your needs assessment and program plan and refined through ongoing evaluation, it will be customized to your patients and your institution. The following steps are examples of some of the major components of the implementation stage:

- Post position (see Appendix B)
- Interview candidates (see Appendices A and F)
- Work with IT staff to have necessary systems, software, and technology equipment in place prior to the navigator's start date.
- Determine what IT systems navigators will need access to and if they will have full or partial access (such as electronic health records)
- Patient navigator begins employment:
  - Orient PN to key staff (provide checklist of staff: front desk, clinicians they will work with directly/indirectly)
  - Orient PN to systems (policies and procedures manual or required trainings)
  - Orient PN to IT systems
  - Have navigator complete 20 hour GW Cancer Institute Online training within two months of hiring date and submit certificate of completion (<http://tinyurl.com/GWOnlineAcademy>)
  - Sign navigator up for AONN+ membership
  - Ensure PN has HIPAA privacy training

## EVALUATE

### Evaluate Patient Navigation Outcomes

Evaluating outcomes is an important part of the program development cycle and success of the program. What you do with the results is equally important. Use the information gathered through the needs assessment, process evaluation and outcomes evaluation to improve your program so that it is achieving the intended results.

Brief tips include:

- Assess your program at regular intervals (e.g., quarterly)
- Refer back to your logic model and evaluation plan
- Keep in mind what stakeholders value and if the information you provide to them is aligned with those values (e.g., cost savings, revenue generated, increased patient satisfaction)

Use of evaluation outcomes may include:

- Inclusion in your organization's annual report, website or other publication
- Justification to administration for program funding and program value
- Inclusion in proposals to funders
- Inclusion in marketing and outreach to patients, caregivers and providers on program effectiveness
- Improvement in quality of life for those affected by cancer – knowing that what you do makes a difference

### Resources

- [The Executive Training on Navigation and Survivorship](#): This free training is open to anyone and includes continuing education credit for nurses and social workers at no cost. Through a series of self-paced modules the training walks participants through: identifying need, planning your program, funding and sustaining your program, evaluating your program and creating a business plan.
- [The Guide for Program Development](#): This free guide accompanies the Executive Training on Navigation and Survivorship and can be used as a standalone resource for creating and sustaining navigation programs.

## SECTION 4: SUSTAINING THE PROFESSION THROUGH EVALUATION AND POLICY

### Understanding the Impact of Navigation

The field of navigation has grown quickly in the last several decades. Because of this rapid growth, there are still questions about how to support navigators long-term as an integral part of the health care team. More data are needed to show stakeholders the importance of the profession. Once these data are available, policy approaches can help to sustain the profession. CCC programs and coalition members can play a role in evaluating navigation programs at their home institutions or more broadly and can use evaluation findings to develop an advocacy agenda to advance the profession at the institutional and state levels.

### Evaluation for Sustainability

Evaluation will show the impact and importance of navigation to administrators, clinicians, policymakers, payers/insurers, patients and others. Navigation services are not currently reimbursable, so hospital and cancer program administrators may be reluctant to provide funding for them. Navigators therefore have to prove their value and worth to ensure a place on the health care team. Many programs are currently funded by grants, which are likely to end eventually. Data to support the value and impact of navigation will provide the foundation on which the profession can ultimately be sustainable through dedicated funding.

In 2015, the GW Cancer Institute conducted a literature review to determine what evaluation has taken place and what outcomes have been identified for navigation. It was found that navigators help patients with a variety of barriers related to: insurance, logistics, finances, communication, education and employment, care coordination, psychosocial challenges and distress and cultural, religious, spiritual and/or personal issues. The review demonstrated that navigation can:

- Be cost-effective
- Improve patient satisfaction
- Improve patient perceptions of patient navigation
- Improve timeliness of care
- Improve care quality and patient-centered outcomes
- Increase adherence to screening, appointments and treatments
- Improve quality of life

There is also evidence that patient navigation reduces hospitalizations, reduces intensive care unit admissions and increases hospice use (Partridge, n.d.).

CCC programs and coalitions can support continued evaluation efforts. In 2016, the GW Cancer Institute will release free tools that can be used by patient navigators and administrators to track the impact of navigation. The tools will be based on the literature review as well as feedback from patient navigators, administrators and others. The GW Cancer Institute plans to pilot test the tools. Your participation in these efforts can help refine

#### COMING 2016

The GW Cancer Institute is creating FREE tools to:

- Help patient navigators **track patient barriers** as well as actions to address barriers
- Help patient **navigators show the impact** of patient navigation
- Help patient navigators and administrators **show the value** of patient navigation

Email [navigation@gwu.edu](mailto:navigation@gwu.edu) if interested in pilot-testing the tool or for notification when it becomes publicly available.

the tools to capture data that helps advance the field. Contact [cancercontrol@gwu.edu](mailto:cancercontrol@gwu.edu) for more information.

## Policy Strategies to Advance Patient Navigation

The term 'policy' can have several meanings. There are different levels of policies which are key to consider. These include:

- *Government/Legal Policy:* State and federal government policies have an impact on health and access to care.
- *Organizational Policy:* This includes policies at places of employment such as hospitals, clinics, community health centers, etc., that codify specific policy positions of the organization.
- *Professional Policy:* Such policies are typically made by an association of professionals and guide professional practice and decorum.
- *Public Policy:* The system of laws that impact health care, health care consumers and health care professionals.
- *Regulatory and Financial Policy:* Once legislation is passed into law, regulations provide the standards under which such laws are implemented into practice.

For policy strategies to be successfully implemented, key information must be gathered at local and state levels. This information includes but is not limited to:

- Community needs assessment to illustrate the need for navigation
- Understanding of current policy and political environments which have the potential to impact health care and the profession of navigation
- Data and evidence to demonstrate navigation value, impact and cost-effectiveness
- Information regarding the current navigation workforce at local and state levels
- Champions in organizations, communities, city councils, legislatures, and others who are supporters of the profession of patient navigation
- Comparison of state level efforts to other state successes and challenges

In addition to the professional policy issues outlined above, it is also critical for patient navigators to communicate to patients, the public and key stakeholders regarding their work. Such awareness raising efforts should focus on the strategic communication of the following:

- Navigation definition and scope (various levels)
- Navigation contributions to the multidisciplinary health care team
- Navigation contributions to improve access to care
- Navigation contributions to reduce health disparities
- Navigation contributions to improve quality of care
- Navigation contributions to reduce the high cost of care

As you work at the state level to support navigation, it might be helpful to think through existing policy approaches that can be used.

### Government/Legal Policy

There have been several efforts at the federal government level that have helped advance navigation. In 2005, the Patient Navigator Outreach and Chronic Disease Act was signed into law to help poor and underserved populations get timely access to care. Around the same

time, several federal agencies began funding patient navigation research studies. In 2005, the National Cancer Institute (along with the American Cancer Society) funded 9 sites as part of the Patient Navigation Research Program, which sought to evaluate the efficacy and cost-effectiveness of patient navigation. In 2006, the Centers for Medicare and Medicaid Services (CMS) funded six 4-year demonstration projects examining patient navigation offered to Medicare or Medicaid beneficiaries with suspected or diagnosed breast, cervical, colorectal, lung or prostate cancers.



In March 2010, the Patient Protection and Affordable Care Act (ACA), also known as the Affordable Care Act or Obamacare, was passed to give more individuals access to affordable, quality health insurance as well as to reduce the growth of health care costs (HHS, 2014). The principles of patient navigation can be found throughout the ACA. The goals of patient navigation—to focus on racial/ethnic minorities and medically underserved populations, promote a more patient-centric health care service delivery model, integrate a fragmented health care system for the benefit of patients, and eliminate barriers to timely and appropriate care—are well-aligned with the intent of the ACA. These objectives are addressed in the law within quality improvement provisions, fostering of new delivery and payment models such as the patient-centered medical home, establishment of the Patient-Centered Outcomes Research Institute and emphasis on reducing racial/ethnic health disparities.

The ACA established the Center for Medicare and Medicaid Innovation (CMMI) to test innovative delivery and payment models, such as Accountable Care Organizations (ACO) and bundled payments, which are designed to promote care coordination in a fragmented system where providers receiving fee-for-service reimbursement have little incentive to coordinate care. CMS is also studying an Oncology Care Model, which includes patient navigation as an essential component.

The 2010 Standard Occupational Classification (SOC) system is used by Federal statistical agencies to classify workers into occupational categories for the purpose of collecting, calculating, or disseminating data. The SOC will be updated in 2018, and the GW Cancer Institute [submitted the documentation for consideration](#) of patient navigation to be included in the SOC. Having an official classification increases the legitimacy of patient navigation as its own profession, and it allows the government to study the profession and include it in counts of types of professionals. The classification also has the potential to lead to further national research.

### **Organizational Policy**

Organizations make policy that can impact navigators. For example, if an organization does not have a job classification for navigator, then they will have difficulty hiring someone with the right skillset and background. They also might make policy about a navigator's job role, how the patient navigation program is structured or whether or not to take Medicaid. It may be necessary to work with organizations to identify and implement policies that support navigators.

## Professional Policy

### Certification

Certification is another way to advance the patient navigator profession. There are several options for certification at the national level. The National Consortium of Breast Centers offers a [Breast Patient Navigator Certification](#). The Academy of Oncology Nurse and Patient Navigators (AONN+) is launching a certification process for all patient navigators and nurse navigators in 2016. States can drive navigators to these certification programs. Several states, such as Massachusetts, Minnesota, Texas and Ohio, have developed certification programs for Community Health Workers. It is important to make sure that state efforts are aligned with national efforts so that there is consistency in navigator roles across the states.

### Scope of Practice

As navigation is not currently a standardized and universally recognized profession, a variety of different individuals fill navigation roles. Patient navigators, in particular, approach their jobs from a variety of backgrounds that contribute to and strengthen their roles with patients. They may live in the communities in which their patients also live, speak the native language of their patients and/or be cancer survivors themselves. Main differences between nurse navigators, social workers and patient navigators are the differing education, skills and training for each; however, all navigators have valuable expertise to offer patients.

#### TIP

It is critical to note that decision makers at all levels are more likely to support navigation services if all navigator types are supportive of each other and more likely to dismiss the critical services of navigators if there is not unity on the importance of these services.

It is important to have a scope of practice for each navigator type. While some duties may overlap, duties also diverge at critical points in the patient's health care experience. Scope of practice is critical for a variety of reasons. First, patients should know what they can expect when working with their navigator. Physicians and the health care team should also have expectations regarding who performs which navigation services. Scope of practice is also critically important for funding and research so that navigators are comparable and research studies are replicable. Ultimately, the professional evidence-base and ability to evaluate navigation services hinges upon common roles and distinctions. Scope of practice should be based on clear competencies, which have been developed for [patient navigators](#) and nurse navigators. See also the Association of Oncology Social Work's [Scope of Practice in Oncology Social Work](#).

## Public Policy

### Licensure

Once the profession has been established and recognized, such as through the SOC system, licensure can take place. However, it is not clear that licensure is the best next step for patient navigation. Licensure is implemented for professionals who interact with the public to protect the health, safety and wellbeing of patients. Licensure is developed, first and foremost, to

protect the public. Licensure does this by identifying individuals who have met established standards of knowledge, skills and practice experience for the profession.

Registration is also an option, which is less rigorous than licensure and does not confer the same status. Registration can be an important first step towards understanding the patient navigation workforce within a state. There is not currently consensus on whether the potential benefits of licensure outweigh the potential risks and costs. A rigorous public debate should be had before moving forward with licensure within a state to ensure that the goals of navigation will be advanced through licensure. Currently no licensing or registration options exist for patient navigators.

#### Potential Benefits of Licensure:

- Most health professions require licensure. Licensure indicates achievement of professional standards.
- Licensure allows the public to hold health professionals accountable.
- Licensure could support the financial value of patient navigators due to the expectation of high quality professional services.

#### Potential Risks and Costs of Licensure:

- Licensure requires professional liability/malpractice insurance for professionals.
- Licensure may pose extra barriers (training and qualifications) for individuals who are already employed as patient navigators. This can slow job growth and limit employment opportunities.
- If reciprocity is not implemented among states, licensure can inhibit relocation. A national licensure compact could address this issue.
- Licensure can reduce market competition.
- Licensure can be costly to organizations, professionals and consumers due to the potential for higher salaries for licensed providers, costs of maintaining the license for licensed professionals and higher payments by consumers for services provided by a licensed provider.

If licensure is pursued, a standard scope of practice must first be developed, and the profession must become a recognized profession to be able to implement licensure.

### **Regulatory and Financial Policy**

Although the American College of Surgeons' Commission on Cancer implemented a [standard requiring a navigation process](#) in accredited institutions by 2015, such services are not currently reimbursed through government health care programs (Medicare or Medicaid) or private insurers. While new models of care delivery are considered, implemented and assessed, hospitals and other health care organizations will have to determine how they will fund patient navigation programs.

The goal of most new health care delivery and payment models (e.g., bundled payments, Oncology Care Model) is value-based care delivery versus the outdated fee-for-service model. Navigators can contribute a great deal towards supporting such models including enhanced care coordination, improved timeliness of care and treatment, reduction in unnecessary health care utilizations and deeper patient understanding and adherence to

treatment goals. Some payers may require certain aspects of navigation to be demonstrated prior to payment for cancer care services, making the navigator role critical to the cancer care team.

### **Medicaid CMS Reimbursement for Community Health Workers**

The Centers for Medicare and Medicaid Services (CMS) provides a potential option for states to seek Medicaid reimbursement for preventive services provided by professionals other than physicians or other licensed professionals, such as community health workers and patient navigators in some cases. States can attain a reimbursement mechanism for preventive services recommended by a physician or other licensed practitioner within their scope of practice, rather than just services provided by these clinicians. Preventive services are further defined in the State Medicaid Manual (chapter 4, section 4385) or in individual states' Medicaid plans.



To pursue the reimbursement option, states must submit a Medicaid State Plan Amendment to CMS that describes: what services will be covered; who will provide them and their required education, training, experience, credentialing or registration; the process for qualifying providers; and the reimbursement method. Reimbursement rates are determined by the State Medicaid agency and vary based on the services provided and costs within the region.

To be eligible for reimbursement, services must both 1) involve direct patient care and 2) be for the express purpose of diagnosing, treating or preventing (or minimizing the adverse effects of) illness, injury or other impairments to an individual's physical or mental health. Based on this eligibility, preventive services that do not involve direct patient care, such as community-level services are not covered. Currently, no uniformly accepted standard exists to define a single set of preventive services or when they should be delivered, so CMS encourages states to consult with local health authorities and organizations to identify the most effective set of preventive services for the state Medicaid population.

The following potential barriers to implementation were adapted from the Texas Department of State Health Services (2014), the Trust for America's Health and Nemours (2013):

1. Ensuring services provided meet the definition of preventive services
2. Ensuring appropriate oversight and safeguards to prevent fraud and abuse
3. Addressing questions and tensions regarding scope of practice issues from licensed providers
4. Educating providers about the change and working with them to develop referral relationships with new providers/programs
5. Determining reimbursement methodology and how to bill for services

6. Addressing State Medicaid agency bandwidth and competing priorities
7. Engaging managed care since the rule is applicable to fee-for-service Medicaid



## Advocacy Strategies for Navigation

There is a need for advocacy to ensure a place for navigation in health care systems, particularly within systems that serve patients who may need navigation services the most. Advocacy is one mechanism to protect and promote the profession. Ultimately, navigators' priority is caring for patients, but it is important to advocate on behalf the profession, as well. Advocacy will help ensure that navigation services are consistently and sustainably invested in and broadly supported so patients receive the services and resources they need to achieve optimal health. The following advocacy plan was adapted from the Prevent Cancer Foundation (2014).

### Step 1: Define Your Role

It is important to be clear about your role in advocacy. This includes why you care about navigation. For instance, are you a navigator, a patient, a physician or a hospital administrator? Outline why navigation matters to you and be clear about your priorities, biases and goals. Your story (and the story of your team members) is critical to advocacy success.

You need to be able to succinctly illustrate why navigation is important. This may include several different factors including the effectiveness of your services as well as the cost-effectiveness of navigation. It also may be important to illustrate why navigation services are worth the cost—because they help patients understand their care options, make informed decisions and navigate exceedingly complex systems.

Your story may include a narrative of positive patient encounters and the resources that you save your employer. Effectiveness and cost-effectiveness can potentially be illustrated in a variety of creative ways including (but not limited to the following):

- Do you have examples of notes or cards from patients thanking you for your services?
- Can you determine the number of patients whose cancer was caught at an early stage, therefore preventing more costly interventions down the road?
- Do you know the number of patients who did not leave to go to another facility due to navigation relationships and efforts?
- Can you quantify the amount of work or time reduced for physicians and other clinic staff due to the work of navigators?
- Can you quantify the amount of money you saved patients through communication with insurance companies, government agencies, pharmaceutical companies, etc.?
- Can you quantify the number of hours you saved patients through your advocacy efforts on their behalf (e.g. time spent on the phone on their behalf)?

- Can you quantify the number of referrals you made for patients and/or their loved ones? Were these referrals made within your organization or to external organizations with services that your organization does not offer?
- Can you quantify the number of patients you worked with to ensure adherence to appointments and/or treatment plans?
- Can you quantify the number of unnecessary utilizations (especially emergency room visits or unplanned hospital admissions) that were prevented because of your services?

## **Step 2: Build Your Team**

Advocacy is a team sport. Regardless of your goal, you cannot achieve it alone. Who is aligned with your position and how can they support navigation? For instance, if you are a navigator, chances are your team will be strengthened through the support of the physicians, nurses, social workers, allied professionals, clinic workers and others that you interact with on a daily basis. Approaching these individuals to join you in your efforts should be done carefully and in an informed manner. Begin with those whom you know are supportive. For instance, chances are you work closely with the social worker (if your organization employs one). Is your relationship collegial and positive? Does the social worker value your services? If so, that would be a great place to start.

Likewise, do you work with specific physicians whom you know value your services because you help them to reduce their workload and better understand the challenges facing their patients? Physicians' voices carry significant weight so it's important to have them on board before moving forward.

Further, if there are other navigators in your system, do not forget about them. They may wholeheartedly support your goals. They may also be wary and not want to rock the boat. Don't forget about the team that stands to win or lose based on your advocacy efforts. Finally, while it may or may not be appropriate to enlist patients in your advocacy efforts, capturing positive feedback regarding navigation is important and can play a critical role in your strategy.

It's also important to understand where hospital administrators and other decision makers stand on your issue. As you assemble your team, keep in mind the overall sentiment toward navigation. If your administration is generally supportive of navigation, it may be easier to build your team. If your administration has reluctantly agreed to include navigation services, but only if they are grant-funded, you may face greater challenges in achieving your advocacy goals (in which case the advocacy process becomes even more important as you build your case in support of navigation).

## **Step 3: Identify the Issue**

What do you want to accomplish? Be clear about your goals. Make sure they are realistic and attainable. Think about who will be supportive of your goals and who might oppose them. Select one to two goals to work on at most. Examples of such goals include the following:

- Secure operational funding for navigation services, rather than grant funding
- Grow navigation services by x number of navigators
- Ensure that all navigators receive competency-based professional training when hired

- Raise navigator salaries by x amount in order to recruit and retain the best and brightest
- Support patient logistical needs through initiatives such as parking validation, transportation support, etc.



As you focus on your issue(s) consider the following:

- Why is this issue important?
- Why should others (including decision makers) care about it?
- What are the repercussions if this issue is not addressed?
- What are the positive outcomes that could occur if this issue is addressed?

#### **Step 4: Target the Audience**

Who can help you accomplish your goal(s)? As noted above, this most likely includes hospital administrators and other decision makers. However, outline all of the stakeholders that could play a role in your efforts. An example may look like this:

- Hospital/organization administrators
- Physicians
- Nurses
- Social workers
- Relevant professionals such as physical therapists, hospice and palliative care professionals, etc.
- Clinic/hospital staff such as schedulers, office managers, etc.
- Your immediate professional circle: Supervisor, colleagues, etc.
- Other navigators
- Patients and/or their loved ones

#### **Step 5: Do Your Homework**

This step is critical. Even if you have the best intentions and the patients' needs at heart, the challenges you are facing exist for a reason. Chances are you won't be able to quickly and easily solve the problem. Going into advocacy with as much information as possible is vital to ensuring your best chance at success. Here are some questions that you should consider before proceeding with any advocacy strategy:

- If there is a problem, why hasn't it already been resolved?
- What is the history behind your issue?
- What are the political pitfalls around your issue?
- What barriers stand in the way of your goals?
- Who are the players involved and where do they stand on the issue(s)? Why do they hold those positions?
- Is there a way you can frame the issue for particular players?
- Do you think their position is flexible, given the right information?

- How might your issue affect each component of the overall system? This includes the people (patients, professionals, administrators, etc.), policies (would organization policies need to be altered to achieve your goal?), political (what does your issue mean to different players and what might they have to change in order to achieve your goal?), and resources (what are the time, money, and personnel resources necessary to achieve your goal?).

Be exhaustive in your search for information, data and answers. Think about all of the questions that you might be asked and prepare to provide answers to those questions. Work with your team to develop comprehensive background information on your issue.

### **Step 6: Set Goals and Objectives**

Once you've defined your top one to two issue(s), clarify your goals and objectives, which will help you address the issue(s). Determine what different levels of success would look like. Below is an example.

- *Issue:* Navigation funding is precarious which creates an environment in which navigators do not feel stable in their positions and are not confident that the administration values their work.
- *Goal:* Secure operational funding for navigation services, rather than grant funding.
- *Objectives:*
  - Provide examples of patient support for navigation services. Highlight positive feedback and outline cases in which navigation services were vital in ensuring positive health outcomes.
  - Provide examples of physician and staff support for navigation services. Highlight positive feedback and outline cases in which navigation services were helpful to physicians and other staff.
  - Quantify the amount of money and resources saved by navigation services (to patients, to the organization, etc.)
  - Illustrate the role navigation plays in positive health outcomes for patients (such as early detection of illness, timeliness of treatment, improved understanding of treatment plan, etc.)
  - Illustrate the positive impact of navigation on organization processes such as appointment retention, patient decision making, timeliness in care, etc.
  - Quantify the reduction in negative outcomes such as patient outmigration.
  - Quantify the improvement in positive outcomes such as patient word of mouth and referrals.

### **Step 7: Prepare Your Position**

Not only do you need to be clear regarding your position, but you also need evidence and data to back it up. You need to be prepared to discuss your position with stakeholders at all levels. Provide enough information (but in a succinct manner) to help them to make informed decisions. Consider the following questions as you prepare your position:

- What issue do you care about and why?
- Why should a particular stakeholder care about the issue? What is their driving motivator (patient care, financial prudence, organizational functioning, etc.)?
- What data (qualitative and quantitative) backs up your position?
- How does your issue impact the system(s) in which you work?

- Has the issue been addressed in the past? If so, what were the outcomes? What contributed to these outcomes and can current efforts build on them or do something differently?
- Do you have examples of other organizations that have been successful in addressing the issue you want to address? If so, what did their process entail?
- What is your “ask?” Be specific and concrete.
- Does your “ask” cost money and if so, where do you propose the money come from?

### **Step 8: Develop a Solution**

Based on all of the information you’ve gathered, how do you propose solving the problem? You should consider a best-case, “in a perfect world” scenario that should serve as a starting point for negotiations. Yes, this should be viewed as a negotiation just like any other “ask” in the workplace. You won’t accomplish your goals simply by asking nicely or wishing it to be. You need a fairly air-tight rationale that can be supported through patients, players, politics and policies.

If the best-case scenario cannot be immediately accomplished, what is your plan B? Be prepared with a secondary ask and be flexible enough that you can meet the needs of relevant stakeholders while also achieving your goals.

### **Step 9: Take Action**

Now that you’ve determined what you want, how to get it and whom to ask, you need to put your plan into motion. If your request is valid and worthwhile, do not be hesitant or shy to ask for what you think is necessary. What process do you need to go through in order to move forward? The first step is often meeting with your direct supervisor and garnering his or her support. Once he or she is on board, there are probably several other individuals that you must approach for political reasons before moving up the organization hierarchy. If you’ve spent time building your team, the groundwork for this process will be built, clearing the way for your efforts. Ultimately, you will need to progress through the proper channels in order to affect change at the highest levels.

### **Step 10: Don’t Give Up**

As with any advocacy efforts, chances are you will not get what you ask for on the first try. However, any step in the right direction should be considered a win. Often stepwise progression towards goals is the most sustainable and ultimately successful strategy towards success.

### **Step 11: Evaluate**

Work with your team to evaluate success. Did you accomplish your goals? If not, why not? If you did, can you build on them in the future? How will you shift your short- and long-term goals at this point? Did your efforts set any changes into motion? For instance, even if you did not achieve your goals, perhaps the administration is now considering navigation as they create future budgets or make determinations about what is important. Chances are regardless of the outcome, your efforts were not in vain and you’ve begun a process to protect and promote the profession of navigation.

## Resources

- [American Cancer Society's Cancer Action Network Workforce Development Policy Brief](#): This policy brief discusses relevant issues that impact the cancer care workforce, including the need for navigators.
- [Association of State and Territorial Health Officials Questions and Answers Regarding Medicaid Rule Change Allowing Reimbursement for Preventive Services Delivered by Non-licensed Providers](#): This Q&A sheet provides answers to questions about how the Medicaid rule change covering preventive services works.
- [Cancer.net's Cancer and the Affordable Care Act](#): This webpage provides an overview of the ACA with a focus on how it impacts people with cancer.
- [Medicaid Reimbursement for Community-Based Prevention Fact Sheet by Trust for America's Health and Nemours](#): This fact sheet outlines the ACA changes that allow for Medicaid reimbursement for preventive services. It also includes a questionnaire to use when drafting the Medicaid State Plan Amendment proposal.
- [CHWs and Medicaid Reimbursement for Prevention Services by the Texas Department of State Health Services](#): This fact sheet discusses the Centers for Medicaid Services rule on preventive services and its effects on reimbursement for services by community health workers.
- [GW Cancer Institute's Addressing Barriers to Care Project](#): This webpage includes information about the institute's project to develop and disseminate free tools for cancer patient navigation programs to demonstrate their impact and value.
- [Prevent Cancer Foundation's Advocacy Toolkit: Guide to Grassroots Leadership](#): This toolkit serves as a resource for advocates interested in cancer prevention and early detection. It is focused mainly on legislative and policy advocacy.

## REFERENCES

- Academy of Oncology Nurse and Patient Navigators. (n.d.). *Mission and vision* [web page]. Retrieved from <http://www.aononline.org/about/mission-and-vision/>
- Berthold, T., DeCarlo, P. (2014). *Training guide to foundations for community health workers*. City College of San Francisco.
- Centers for Disease Control and Prevention. (1999). *Framework for program evaluation in public health*. *MMWR* 48, RR-11.
- Centers for Disease Control and Prevention. (2012). *Develop SMART objectives*. Retrieved from [http://www.cdc.gov/phcommunities/resourcekit/evaluate/smart\\_objectives.html](http://www.cdc.gov/phcommunities/resourcekit/evaluate/smart_objectives.html)
- Commission on Cancer (2012). *Cancer program standards 2012: Ensuring patient-centered care*. Retrieved from <https://www.facs.org/~media/files/quality%20programs/cancer/coc/programstandards2012.a shx>
- Department of Health and Human Services. (n.d.). *Social determinants of health*. Retrieved from <http://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health>
- Eberly Center for Teaching Excellence at Carnegie Mellon University. (n.d.). *Articulate your learning objectives*. Retrieved from <https://www.cmu.edu/teaching/designteach/design/learningobjectives.html>
- Freeman, H.P. & Rodriguez, R.L. (2011). History and principles of patient navigation. *Cancer*, 117(15 Suppl), 3539-3542. <https://dx.doi.org/10.1002/cncr.26262>
- Huddle. (2009). *10 quick and easy team building exercises [Part 2]*. Retrieved from <http://wheniwork.com/blog/team-building-games>
- National Cancer Institute. (2008). *Cancer health disparities*. Retrieved from <http://www.cancer.gov/cancertopics/factsheet/disparities/cancer-health-disparities>
- National Cancer Institute (2015). *Cancer health disparities definitions*. Retrieved from <http://www.cancer.gov/aboutnci/organization/crchd/about-health-disparities/definitions>
- Partridge, E. (n.d.). *CMS Innovation Challenge grant: Deep South Cancer Navigation Network*. [PowerPoint presentation].
- Prevent Cancer Foundation. (2014). *Advocacy toolkit: Guide to grassroots leadership*. Retrieved from <http://preventcancer.org/wp-content/uploads/2014/12/Prevent-Cancer-Advocacy-Toolkit.pdf>
- Ralph Lauren Center for Cancer Care and Prevention (n.d.). *Patient navigation*. Retrieved from [http://ralphlaurencenter.org/services\\_patient\\_origin.asp](http://ralphlaurencenter.org/services_patient_origin.asp)
- Registered Nurses' Association of Ontario. (n.d.). *Best practices toolkit, the shield activity*. Retrieved from [http://ltctoolkit.rnao.ca/sites/ltc/files/resources/CCCare/EducationResources/EdResources/PD F37\\_IcebreakersShieldActivity.pdf](http://ltctoolkit.rnao.ca/sites/ltc/files/resources/CCCare/EducationResources/EdResources/PD F37_IcebreakersShieldActivity.pdf)
- Texas Department of State Health Services. (2014). *CHWs and Medicaid reimbursement for prevention services*. Retrieved from <http://www.dshs.state.tx.us/WorkArea/DownloadAsset.aspx?id=8589997601>
- The George Washington University Cancer Institute. (2013). *Best practices in patient navigation and cancer survivorship survey results*. Retrieved from: [https://smhs.gwu.edu/gwci/sites/gwci/files/Best\\_Practices\\_Results\\_Summary-Final.pdf](https://smhs.gwu.edu/gwci/sites/gwci/files/Best_Practices_Results_Summary-Final.pdf)

- Trust for America's Health and Nemours (2013). *Medicaid reimbursement for community-based prevention*. Retrieved from <http://www.astho.org/Community-Health-Workers/Medicaid-Reimbursement-for-Community-Based-Prevention/>
- U.S. Department of Health and Human Services. (2014). *Key features of the Affordable Care Act*. Retrieved from [http://www.hhs.gov/health\\_care/facts-and-features/key-features-of-aca/index.html](http://www.hhs.gov/health_care/facts-and-features/key-features-of-aca/index.html)
- When I Work. (2015). *An epic list of team building games*. Retrieved from <http://wheniwork.com/blog/team-building-games/>
- Willis, A., Reed, E., Pratt-Chapman, M., Kapp, H., Hatcher, E., Vaitones, V.... Washington, E. (2013). Development of a framework for patient navigation: Delineating roles across navigator types. *Journal of Oncology Navigation & Survivorship*, 4(6), 20-26.
- Wrike Project Management Blog. (2015). *Ultimate guide to team building activities that don't suck*. Retrieved from <https://www.wrike.com/blog/ultimate-guide-team-building-activities>

## APPENDICES

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## Appendix A: Core Competencies for Non-Clinically Licensed Patient Navigators

### Domain 1: Patient Care

Facilitate patient-centered care that is compassionate, appropriate and effective for the treatment of cancer and the promotion of health.

- 1.1 Assist patients in accessing cancer care and navigating health care systems. Assess barriers to care and engage patients and families in creating potential solutions to financial, practical and social challenges.
- 1.2 Identify appropriate and credible resources responsive to patient needs (practical, social, physical, emotional, spiritual) taking into consideration reading level, health literacy, culture, language and amount of information desired. For physical concerns, emotional needs or clinical information, refer to licensed clinicians.
- 1.3 Educate patients and caregivers on the multi-disciplinary nature of cancer treatment, the roles of team members and what to expect from the health care system. Provide patients and caregivers evidence-based information and refer to clinical staff to answer questions about clinical information, treatment choices and potential outcomes.
- 1.4 Empower patients to communicate their preferences and priorities for treatment to their health care team; facilitate shared decision making in the patient's health care.
- 1.5 Empower patients to participate in their wellness by providing self-management and health promotion resources and referrals.
- 1.6 Follow up with patients to support adherence to agreed-upon treatment plan through continued non-clinical barrier assessment and referrals to supportive resources in collaboration with the clinical team.

### Domain 2: Knowledge for Practice

Demonstrate basic understanding of cancer, health care systems and how patients access care and services across the cancer continuum to support and assist patients.

NOTE: This domain refers to foundational knowledge applied across other domains.

- 2.1 Demonstrate basic knowledge of medical and cancer terminology.
- 2.2 Demonstrate familiarity with and know how to access and reference evidence-based information regarding cancer screening, diagnosis, treatment and survivorship.
- 2.3 Demonstrate basic knowledge of cancer, cancer treatment and supportive care options, including risks and benefits of clinical trials and integrative therapies.
- 2.4 Demonstrate basic knowledge of health system operations.
- 2.5 Identify potential physical, psychological, social and spiritual impacts of cancer and its treatment.
- 2.6 Demonstrate general understanding of health care payment structure, financing, and where to refer patients for answers regarding insurance coverage and financial assistance.

### Domain 3: Practice-Based Learning and Improvement

Improve patient navigation process through continual self-evaluation and quality improvement. Promote and advance the profession.

- 3.1 Contribute to patient navigation program development, implementation and evaluation.
- 3.2 Use evaluation data (barriers to care, patient encounters, resource provision, population health disparities data and quality indicators) to collaboratively improve navigation process and

- participate in quality improvement.
- 3.3 Incorporate feedback on performance to improve daily work.
- 3.4 Use information technology to maximize efficiency of patient navigator's time.
- 3.5 Continually identify, analyze and use new knowledge to mitigate barriers to care.
- 3.6 Maintain comprehensive, timely and legible records capturing ongoing patient barriers, patient interactions, barrier resolution and other evaluation metrics and report data to show value to administrators and funders.
- 3.7 Promote navigation role, responsibilities and value to patients, providers and the larger community.

#### Domain 4: Interpersonal and Communication Skills

Demonstrate interpersonal and communication skills that result in the effective exchange of information and collaboration with patients, their families and health professionals.

- 4.1 Assess patient capacity to self-advocate; Help patients optimize time with their doctors and treatment team (e.g. prioritize questions, clarify information with treatment team).
- 4.2 Communicate effectively with patients, families and the public to build trusting relationships across a broad range of socioeconomic and cultural backgrounds.
- 4.3 Employ active listening and remain solutions-oriented in interactions with patients, families and members of the health care team.
- 4.4 Encourage active communication between patients/families and health care providers to optimize patient outcomes.
- 4.5 Communicate effectively with navigator colleagues, health professionals and health related agencies to promote patient navigation services and leverage community resources to assist patients.
- 4.6 Demonstrate empathy, integrity, honesty and compassion in difficult conversations.
- 4.7 Know and support National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care to advance health equity, improve quality and reduce health disparities.
- 4.8 Apply insight and understanding about emotions and human responses to emotions to create and maintain positive interpersonal interactions.

#### Domain 5: Professionalism

Demonstrate a commitment to carrying out professional responsibilities and an adherence to ethical principles.

- 5.1 Apply knowledge of the difference in roles between clinically licensed and non-licensed professionals and act within professional boundaries
- 5.2 Build trust by being accessible, accurate, supportive and acting within scope of practice.
- 5.3 Use organization, time management, problem-solving and critical thinking to assist patients efficiently and effectively.
- 5.4 Demonstrate responsiveness to patient needs within scope of practice and professional boundaries.
- 5.5 Know and support patient rights.
- 5.6 Demonstrate sensitivity and responsiveness to a diverse patient population, including but not limited to diversity in gender, age, culture, race, religion, abilities and sexual orientation.

- 5.7 Demonstrate a commitment to ethical principles pertaining to confidentiality, informed consent, business practices and compliance with relevant laws, policies and regulations (e.g. HIPAA, agency abuse reporting rules, Duty to Warn, safety contracting).
- 5.8 Perform administrative duties accurately and efficiently.

#### Domain 6: Systems-Based Practice

Demonstrate an awareness of and responsiveness to the larger context and system of health care, as well as the ability to call effectively on other resources in the system to provide optimal health care.

- 6.1 Support a smooth transition of patients across screening, diagnosis, active treatment, survivorship and/or end-of-life care, working with the patient's clinical care team.
- 6.2 Advocate for quality patient care and optimal patient care systems.
- 6.3 Organize and prioritize resources to optimize access to care across the cancer continuum for the most vulnerable patients.

#### Domain 7: Interprofessional Collaboration

Demonstrate ability to engage in an interprofessional team in a manner that optimizes safe, effective patient- and population-centered care.

- 7.1 Work with other health professionals to establish and maintain a climate of mutual respect, dignity, diversity, ethical integrity and trust.
- 7.2 Use knowledge of one's role and the roles of other health professionals to appropriately assess and address the needs of patients and populations served to optimize health and wellness.
- 7.3 Participate in interprofessional teams to provide patient- and population-centered care that is safe, timely, efficient, effective and equitable.

#### Domain 8: Personal and Professional Development

Demonstrate qualities required to sustain lifelong personal and professional growth.

- 8.1 Set learning and improvement goals. Identify and perform learning activities that address one's gaps in knowledge, skills, attitudes and abilities.
- 8.2 Demonstrate healthy coping mechanisms to respond to stress; employ self-care strategies.
- 8.3 Manage possible and actual conflicts between personal and professional responsibilities.
- 8.4 Recognize that ambiguity is part of patient care and respond by utilizing appropriate resources in dealing with uncertainty.

## Appendix B: Sample Patient Navigator Job Description

### BASIC FUNCTION

The Patient Navigator works in a dynamic health care environment within one or more departments providing one-on-one assistance to patients, navigating them through the health care system to ensure timely screening, diagnosis, treatment and/or post-treatment cancer care and supportive services. S/he works with other health care professionals to establish and maintain a climate of mutual respect, dignity, diversity, ethical integrity and trust and participates in multi-disciplinary teams to provide patient care that is safe, timely, efficient, effective and equitable. S/he uses knowledge of one's role and the roles of other health care professionals to appropriately assess and address the needs of patients served to optimize health and wellness. S/he is expected to set learning and improvement goals; identify and perform learning activities that address one's gaps in knowledge, skills, attitudes and abilities; and respond to feedback to improve professional performance and patient care.

### CHARACTERISTIC DUTIES

- Assist patients in accessing cancer care and navigating health care systems
- Assess barriers to care and engage patients and families in creating potential solutions to financial, practical and social challenges
- Identify appropriate and credible resources responsive to patient needs (practical, social, physical, emotional, spiritual), taking into consideration reading level, health literacy, culture, language and amount of information desired; refer to licensed clinicians for physical concerns, emotional needs or clinical education
- Educate patients and caregivers on the multi-disciplinary nature of cancer treatment, the roles of team members and what to expect from the health care system
- Provide patients and caregivers evidence-based information and refer to clinical staff to answer questions about clinical information, treatment choices and potential outcomes
- Encourage patients to communicate their preferences and priorities for treatment to their health care team; facilitate shared decision making in the patient's health care
- Encourage patients to participate in their wellness by providing self-management and health promotion resources and referrals
- Follow up with patients to support adherence to agreed-upon treatment plan through continued non-clinical barrier assessment and referrals to supportive resources in collaboration with the clinical team
- Contribute to patient navigation program development, implementation and evaluation
- Assess patient capacity to self-advocate; help patients optimize time with their doctors and treatment team (e.g. prioritize questions, clarify information with treatment team)
- Encourage active communication between patients/families and health care providers to optimize patient outcomes

### RELATED DUTIES

- Performs special project assignments required to support the implementation and evaluation of patient navigation
- Assists with care coordination of patients

- Enhances professional knowledge/skills by identifying and participating in continuing education opportunities
- Performs other non-clinical work related duties as requested

### **SUPERVISION RECEIVED**

Supervision is received from \_\_\_\_\_

### **QUALIFICATIONS AND SKILLS REQUIRED**

Basic understanding of medical terminology, health care systems and health care financing required. Proficiency with a personal computer is necessary. Demonstrated fluency in English/[**Insert any language requirements here**]. In addition, the patient navigator must be able to:

- Work cooperatively and communicate effectively with a wide range of individuals, including patients and family members from diverse socioeconomic and cultural backgrounds, health care professional colleagues and external health- and service-focused organizations
- Employ active listening and remain solutions-oriented in interactions with patients, families and members of the health care team
- Demonstrate empathy, integrity, honesty and compassion in difficult conversations
- Apply insight and understanding about emotions and human responses to emotions to create and maintain positive interpersonal interactions
- Apply knowledge of the difference in roles between clinically licensed and non-licensed professionals and act within professional boundaries
- Demonstrate excellent communication, organizational, and interpersonal skills

### **WORKING CONDITIONS**

The incumbent performs job duties in a normal business office environment and/or in a community-based setting exterior to the normal business office environment. Tasks are generally carried out in a sedentary format within the business environment. This involves working while sitting at a desk for extended periods of time; exterior working environments require standing and/or walking for extended periods of time. Typically, the incumbent will not be exposed to adverse weather conditions or physical activities in order to perform the job other than occasionally lifting office supply items that may weigh up to 20 pounds. The incumbent will be required to attend meetings in other offices, or deliver and/or retrieve information from other offices around campus and within community-based settings.

## Appendix C: Patient Navigation Case Studies for Role Play and Group Discussions

### Case Study Role Playing Prompt

Two patient navigators should be selected to participate in a role-playing exercise based on one of the case studies below. If there are no volunteers to role-play in front of the group, participants can be divided into pairs and they can role play together before a pair is asked to role play for the whole group. Based on the outlined scenario, one person should pretend to be the patient and the other person should pretend to be the patient navigator. Use the discussion questions to prompt interactions between patient and navigator.

Following the role-play it is important for the leader to facilitate a discussion about the exercise.

- a. What concerns do patient navigators have about the patient?
- b. What did the patient navigator do in the role-play that was helpful?
- c. Did it seem like trust was established between the navigator and patient?
- d. If the patient navigator and patient did not seem to establish a useful relationship or if the patient navigator did not properly address the patient's concerns, what could be done differently?
- e. What other questions could the patient navigator have asked?
- f. What do you think are the patient's major concerns? Why do you think he or she feels this way? How did or could the patient navigator address and potentially allay these concerns?
- g. What non-verbal cues were present?
- h. What do you think the patient outcome might be?
- i. What next steps should be taken?
- j. What themes were constant in the role-plays?
- k. Did the patient navigator adhere to appropriate boundaries?

### Case Study #1

Emily is a 32 year-old married woman who is six months pregnant with her second child. Emily mentioned in passing to her husband, Thomas, that she had felt a small lump in her right breast for several months. Since this was her second time being pregnant, Emily knew that her body was going through changes and she wasn't very worried about the lump. Thomas encouraged Emily to ask her OB/GYN to inspect the lump at her next appointment and Emily agreed, mostly to comfort Thomas. A few weeks later at her regular appointment, Emily mentioned the lump to her OB/GYN, Dr. Powell, who examined Emily's breast. Although he did not like what he felt, he told her not to worry. He referred Emily for further tests, and a several days later Emily was diagnosed with stage II breast cancer.

Emily's primary focus is on her baby and two-year old son. She wants to remain healthy throughout her pregnancy and is concerned about exposing her baby to cancer treatments and stress. Emily seems confused and overwhelmed. She has been hesitant to make any decisions about cancer treatment and as a result, her relationship with her husband has become very strained. Thomas is worried about Emily as well as his children. Emily's oncologist has laid out her options and has asked you to comfort her and her family as they make these important health care decisions.

### *Discussion Questions*

1. What is your role in Emily's care? How does this role align with the scope of practice for a patient navigator without a clinical license?
2. At what point should you refer Emily to another health care team member?
3. Is your client Emily, her family, or both?
4. Are you bound by confidentiality if Emily confides in you about a decision that will impact her whole family?
5. What boundaries are important to consider as Emily makes her decision?

### **Case Study #2**

Larry is a 58-year old recently divorced man. Larry's wife was emotionally abusive and he is proud of himself for leaving her and excited to start a new chapter in his life. Larry enjoys his job, interacting with customers, at a retail store although he earns just above minimum wage. He values time with friends and has been going out and enjoying life as a single man.

Recently, however, Larry hasn't been feeling well. He thought he was just moving too fast and needed to slow down a bit. However, six months have passed and Larry still feels fatigued. After standing on his feet all day, he often goes to bed without eating, has lost weight, and always feels weak. Larry noticed a yellowing of his eyes and skin and decided he needed to figure out what was wrong.

Larry felt so poorly that he went to the emergency room. Tests showed that he was positive for hepatitis-C, and the doctor told him he had been for quite a while because he also had liver cancer. Larry is devastated. He is confused by the diagnosis and asks you repeatedly how this could happen.

### *Discussion Questions*

1. Larry is bewildered by the diagnosis because hepatitis-C carries such stigma. He tells you he's never used drugs and doesn't know how this could have happened. How would you work with Larry to help him deal with the situation?
2. You help Larry to deduce that he probably contracted hepatitis-C from a blood transfusion he had in the 1980s before the blood supply was tested. Larry is furious and wants to pursue legal action. What do you say to Larry?
3. Larry has very limited resources and is concerned about paying for treatment. How will you assist him?
4. Although Larry is happy about his decision to leave his wife, he's made comments that he needs her support through his treatment. Since he has indicated to you that she was abusive in the past, how would you address his desire to reach out to his ex-wife?

### **Case Study #3**

Miguel is a 62 year-old single Hispanic man who is undocumented and has limited proficiency in English. He has worked construction jobs outdoors since he immigrated to the United States 25 years ago. For months, Miguel has felt a rough, raised patch of skin on the back of his neck. He has scratched it so often that it has led to bleeding several times. One day Miguel's boss told him that he should get his sore checked out because it didn't look good. Miguel went to the emergency room and was eventually informed that he has melanoma. He was referred to the community cancer clinic where you work as a patient navigator.

During his first visit, Miguel expresses that he is very upset. He can't believe that he has skin cancer. No one ever told him to wear sunscreen or that he would be at risk for this kind of cancer. He has already missed several days of work and living paycheck to paycheck, he can't be out much longer. He also is concerned about how he will pay for treatment since he is uninsured and if he will get in trouble for being in the country without documentation.

#### *Discussion Questions*

1. Miguel needs treatment immediately but is uninsured. What steps will you take to help him access care?
2. One of Miguel's major concerns is legal status. How can you work with him to address his fears about potential deportation?
3. Miguel is going to need to take time off from work for treatment and healing. He is worried about the loss of income as well as the potential to get fired. What would you do to support Miguel?
4. Miguel is single without family in the United States. Where could he go for support?

#### **Case Study #4**

Maya is a 19 year-old woman in her second year of college. She earns excellent grades, is on her school's soccer team and excels at almost everything she does. As an only child Maya is close with both of her parents, but she chose to go to school on the west coast while they stayed in her hometown back east. Maya's friends have noticed that she's been short of breath and has lost some weight recently. She has also complained of feeling lethargic and achy. When she was too weak to play in her soccer game, Maya's coach took her to student health to try to figure out what was wrong.

Maya was diagnosed with non-Hodgkin lymphoma and she was transferred to the academic medical center where you work as a patient navigator. Maya is terrified and hasn't called her parents yet because she doesn't want to upset them. She has quickly come to rely on you as her go-to resource.

#### *Discussion Questions*

1. Maya has asked you to be with her when she calls her parents. What will you say to prepare her for this conversation?
2. Based on what Maya has told you, her parents will fly to her immediately. How will you prepare to help them?
3. Even after her parents arrive, Maya seems to be relying heavily on you for support. You sense that her parents are hurt and you want to help the family through this challenging time. What would you say to Maya to help her communicate with her parents?
4. Maya's parents want her to return home to the east coast and take a leave of absence from school. Maya wants to receive her treatment at the academic medical center on campus and stay near her friends and her new life. What would you say to facilitate this conversation and help them make a decision?

#### **Case Study #5**

Clinton is an 85 year-old African American man with metastatic lung cancer. His doctor believes that he will only survive for a month or two longer. Clinton has been a lifelong

smoker, starting as a teenager. Despite his grim prognosis, he is a cheerful man, comfortable that he has led a good life. He has been married to Celeste for over 60 years and they have four children and nine grandchildren. He has enjoyed his family, friends and career and expresses no regrets. He feels like 85 good years is more than any person can ask for in life.

However, Celeste is furious with Clinton. She has always told him she didn't like his smoking and she's now blaming him for his disease. Celeste always accompanies Clinton to his appointments but as Clinton's navigator you can sense her frustration and anger. Clinton is interested in exploring hospice care but Celeste can't seem to let go and allow him to make this decision.

#### *Discussion Questions*

1. Although Clinton is not worried for himself, he is concerned about how Celeste will handle it if he dies. How would you address Clinton's concerns while respecting his wishes to explore his options to enter hospice care?
2. Clinton has given you permission to help connect Celeste with resources that she might find helpful to process her grief. What would you do to help her?
3. You think that Celeste might find comfort in her children and grandchildren but she worried about upsetting them and hasn't kept them updated about Clinton's condition. How would you work with her to help her with this concern?
4. Since Clinton is facing death, what other issues should you discuss with him and Celeste?

#### **Case #6**

Lena is a 37 year-old single mother of three. Lena struggled her whole life to make ends meet and has lived in a cycle of poverty since childhood. Like her family members, Lena did not graduate from high school and works at a local convenience store. Her grandmother watches the children when Lena is at work, but Lena is worried about her increasing frailty and ability to keep up with the kids.

Lena believes in hard work and the only "handouts" she receives are in the form of the children's health insurance plan for her children and Medicaid for herself. She has always refused to apply for "welfare of any kind" including foods stamps or Temporary Assistance for Needy Families.

Lena was recently driving home from work and she felt numbness and tingling down one side of her body including in her foot. It caused her to hit the gas instead of the brake and she totaled her car. Lena ended up in the emergency room and ultimately an MRI revealed that Lena has a brain tumor.

The hospital where Lena was treated does not accept Medicaid patients, so she cannot be treated there. Lena is referred to the hospital where you work because of the charity program.

#### *Discussion Questions*

1. Lena has very low health literacy and is terrified. She thinks she is going to die. How do you comfort her?
2. Lena has very few resources. She is concerned about making money to feed her children as well as to replace the car that was totaled. What would you do to help her?

3. Lena is standing firm that she won't accept handouts. How do you respect her concerns while helping her access the resources she needs?
4. Lena is the 5th patient this month without health insurance. Hospital administrators are worried that they cannot continue to pay for this free treatment. How would you address their concerns?

### **Case Study #7**

Carl is a 75 year-old retired teacher and football coach. He prides himself on being "a guy's guy" and enjoys sports, camping and having cookouts with family and friends. Carl has been married to Thuy for 40 years and they have a large, close-knit family with five children and 12 grandchildren. Although Carl has never been wealthy, he has always been proud of his work and has cherished his family.

Carl has not, however, always put his health first. He has been overweight most of his life and regularly enjoys red meat, beer and the occasional cigar. Thuy has pushed Carl to take better care of himself and to get to the doctor over the years but his stubbornness persisted and he hasn't had a checkup in over five years.

Carl reluctantly told Thuy that he has been having bowel issues—the consistency of his stool has changed, he's been experiencing abdominal pain and he's seen blood in his stool. Thuy called the doctor and insisted that Carl go in for a checkup. Tests revealed that Carl has stage IV colon cancer and his prognosis is grim.

In addition to his health challenges, Carl is refusing to spend money out of pocket for treatment. His insurance covers some, but not all, of his health care needs and he doesn't want to "put his family out" by tapping into savings.

### **Discussion Questions**

1. Carl is reluctant to discuss his cancer or his feelings. As his patient navigator, you are finding it difficult to connect with him. What can you do to create a relationship to help Carl?
2. Thuy is upset and scared. She's also confided in you that she is frustrated with Carl's attitude and behavior. How can you help Carl and his family discuss Carl's diagnosis?
3. You can tell Carl cares deeply about his family, especially Thuy. You understand why he doesn't want to utilize savings to pay for his care, but you also know that Thuy would spend it all to help her husband. How can you help to facilitate a conversation regarding finances?
4. If Carl doesn't think he needs a patient navigator, at what point do you have to respect his wishes and step away from working with him?

## Appendix D: Group Activities for Navigation Networks

Group activities can help navigators interact with and learn from each other. Potential group activities could include:

### *Team Building*

1. Divide participants into small groups of four to eight people.
2. Pass out large pieces of flipchart paper and markers to each group.
3. Ask each group share their individual strengths and positive attributes that help them succeed at their job. Once everyone has shared this information, pass out a new piece of large paper.
4. Ask each group to then create a super group member that encompasses all of the strengths and attributes they shared. Ask the group to draw this person and give him or her a name.
5. Each group should share the story of their new group member and discuss how as a team, they can build on one another's strengths. (adapted from Huddle, 2009).

### *Problem Solving*

This activity can help navigators build problem solving skills and is particularly useful when there are dominant personalities within the group and you'd like to involve all participants.

1. Utilize a hypothetical case study that is complicated and involves a patient with many different barriers that are challenging to address. Read it aloud to the group. Ask participants to consider how they would help the patient address his or her barriers.
2. Request a volunteer to start problem solving. Give the volunteer a piece of paper and ask them to briefly write down one way in which they would help the patient address one of his or her barriers.
3. Ask the first participant to pass the paper to the person sitting next to them. That participant will build on the first person's answer and write down another way to help the patient.
4. Continue passing the paper until participants can come up with no more ways to address the patient's barriers.
5. Ask for the paper back and facilitate the problem solving process outlined by the patient navigators (Adapted from When I Work, 2015).

### *Leadership*

Ask for group volunteers to share two different aspects of their personality. First, they should present on a professional topic of interest on which they have expertise. Second, they should present about something important to them personally. They can discuss how their personal subject informs how they approach their professional work.

### *Brainstorming*

1. Think about a question that is professionally relevant but challenging to answer. For instance, how can we prove the value (effectiveness and cost-effectiveness) of patient navigation?
2. Ask group participants to answer with the first ideas they come up with. Write these ideas on a flip chart or white board.
3. Ask group participants to split into pairs or smaller groups and brainstorm based on the initial ideas to build on the quick response answers.
4. Come back together as one larger group to develop a consensus-based answer to the question.

### *Creativity*

1. Ask group participants to create a personal coat of arms. You can pass out pieces of paper with an outline of a coat of arms on it. It should be divided into four segments which are titled: (1) What I'm most proud of in my work life; (2) What areas of my work life I enjoy the most; (3) How I would like to be remembered by my patients and colleagues; and (4) What keeps me coming back to work every day.
2. Group participants should spend time either writing, drawing, or otherwise representing their answers to these questions.
3. Ask each group participant to discuss their personal coat of arms with their colleagues (Adapted from Registered Nurses' Association of Ontario, n.d.).

### *Communication*

1. Consider different pairs of words. For instance, salt and pepper or peanut butter and jelly. Create enough words for each person in your group and print them on pieces of paper.
2. Randomly tape one word to each person's back. They need to figure out their word by asking other participant's yes or no questions.
3. Once participants have successfully guessed their word, they then need to find their pair.
4. The first pairs to find each other can begin to sit down in succession and discuss other things they have in common (Adapted from Wrike Project Management Blog, 2015).

### *Cultural Sensitivity*

Ask group members to volunteer to share a time when they did not know how to assist a patient dealing with a barrier related to a specific personal characteristic such as his or her race/ethnicity, age, sexual orientation, religion/spirituality, disability status, weight, etc. The group member should discuss what they learned from the experience and how they would address a similar challenge in the future.

## Appendix E: Patient Navigator Competency Self-Assessment Tool

Based on the GW Cancer Institute [Core Competencies for Non-Clinically Licensed Patient Navigators](#), this tool can be used by patient navigators to assess their level of competency. For each competency statement, indicate whether the competency is an area for improvement, whether you are satisfactory in that competency or whether you are proficient in that competency. When you have completed the self-assessment you can identify topics for additional training and education.

Domain 1: Patient Care				
Facilitate patient-centered care that is compassionate, appropriate and effective for the treatment of cancer and the promotion of health.				
Competency		Area for Improvement	Satisfactory	Proficient
1.1	Assist patients in accessing cancer care and navigating health care systems. Assess barriers to care and engage patients and families in creating potential solutions to financial, practical and social challenges.			
1.2	Identify appropriate and credible resources responsive to patient needs (practical, social, physical, emotional, spiritual) taking into consideration reading level, health literacy, culture, language and amount of information desired. For physical concerns, emotional needs or clinical information, refer to licensed clinicians.			
1.3	Educate patients and caregivers on the multi-disciplinary nature of cancer treatment, the roles of team members and what to expect from the health care system. Provide patients and caregivers evidence-based information and refer to clinical staff to answer questions about clinical information, treatment choices and potential outcomes.			
1.4	Empower patients to communicate their preferences and priorities for treatment to their health care team; facilitate shared decision making in the patient's health care.			
1.5	Empower patients to participate in their wellness by providing self-management and health promotion resources and referrals.			
1.6	Follow up with patients to support adherence to agreed-upon treatment plan through continued non-clinical barrier assessment and referrals to supportive resources in collaboration with the clinical team.			
Domain 2: Knowledge for Practice				
Demonstrate basic understanding of cancer, health care systems and how patients access care and services across the cancer continuum to support and assist patients.				
Competency		Area for Improvement	Satisfactory	Proficient
2.1	Demonstrate basic knowledge of medical and cancer terminology.			
2.2	Demonstrate familiarity with and know how to access and reference evidence-based information regarding cancer screening, diagnosis, treatment and survivorship.			

2.3	Demonstrate basic knowledge of cancer, cancer treatment and supportive care options, including risks and benefits of clinical trials and integrative therapies.			
2.4	Demonstrate basic knowledge of health system operations.			
2.5	Identify potential physical, psychological, social and spiritual impacts of cancer and its treatment.			
2.6	Demonstrate general understanding of health care payment structure, financing, and where to refer patients for answers regarding insurance coverage, and financial assistance.			

### Domain 3: Practice-Based Learning and Improvement

Improve patient navigation process through continual self-evaluation and quality improvement. Promote and advance the profession.

Competency		Area for Improvement	Satisfactory	Proficient
3.1	Contribute to patient navigation program development, implementation and evaluation.			
3.2	Use evaluation data (barriers to care, patient encounters, resource provision, population health disparities data and quality indicators) to collaboratively improve navigation process and participate in quality improvement.			
3.3	Incorporate feedback on performance to improve daily work.			
3.4	Use information technology to maximize efficiency of patient navigator's time.			
3.5	Continually identify, analyze and use new knowledge to mitigate barriers to care.			
3.6	Maintain comprehensive, timely and legible records capturing ongoing patient barriers, patient interactions, barrier resolution and other evaluation metrics and report data to show value to administrators and funders.			
3.7	Promote navigation role, responsibilities and value to patients, providers and the larger community.			

### Domain 4: Interpersonal and Communication Skills

Demonstrate interpersonal and communication skills that result in the effective exchange of information and collaboration with patients, their families and health professionals.

Competency		Area for Improvement	Satisfactory	Proficient
4.1	Assess patient capacity to self-advocate; Help patients optimize time with their doctors and treatment team (e.g. prioritize questions, clarify information with treatment team).			
4.2	Communicate effectively with patients, families and the public to build trusting relationships across a broad range of socioeconomic and cultural backgrounds.			

4.3	Employ active listening and remain solutions-oriented in interactions with patients, families and members of the health care team.			
4.4	Encourage active communication between patients/families and health care providers to optimize patient outcomes.			
4.5	Communicate effectively with navigator colleagues, health professionals and health related agencies to promote patient navigation services and leverage community resources to assist patients.			
4.6	Demonstrate empathy, integrity, honesty and compassion in difficult conversations.			
4.7	Know and support National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care to advance health equity, improve quality and reduce health disparities.			
4.8	Apply insight and understanding about emotions and human responses to emotions to create and maintain positive interpersonal interactions.			
<b>Domain 5: Professionalism</b>				
Demonstrate a commitment to carrying out professional responsibilities and an adherence to ethical principles.				
<b>Competency</b>		<b>Area for Improvement</b>	<b>Satisfactory</b>	<b>Proficient</b>
5.1	Apply knowledge of the difference in roles between clinically licensed and non-licensed professionals and act within professional boundaries			
5.2	Build trust by being accessible, accurate, supportive and acting within scope of practice.			
5.3	Use organization, time management, problem-solving and critical thinking to assist patients efficiently and effectively.			
5.4	Demonstrate responsiveness to patient needs within scope of practice and professional boundaries.			
5.5	Know and support patient rights.			
5.6	Demonstrate sensitivity and responsiveness to a diverse patient population, including but not limited to diversity in gender, age, culture, race, religion, abilities and sexual orientation.			
5.7	Demonstrate a commitment to ethical principles pertaining to confidentiality, informed consent, business practices and compliance with relevant laws, policies and regulations (e.g. HIPAA, agency abuse reporting rules, Duty to Warn, safety contracting).			
5.8	Perform administrative duties accurately and efficiently.			

**Domain 6: Systems-Based Practice**

Demonstrate an awareness of and responsiveness to the larger context and system of health care, as well as the ability to call effectively on other resources in the system to provide optimal health care.

Competency	Area for Improvement	Satisfactory	Proficient
6.1 Support a smooth transition of patients across screening, diagnosis, active treatment, survivorship and/or end-of-life care, working with the patient's clinical care team.			
6.2 Advocate for quality patient care and optimal patient care systems.			
6.3 Organize and prioritize resources to optimize access to care across the cancer continuum for the most vulnerable patients.			

**Domain 7: Interprofessional Collaboration**

Demonstrate ability to engage in an interprofessional team in a manner that optimizes safe, effective patient- and population-centered care.

Competency	Area for Improvement	Satisfactory	Proficient
7.1 Work with other health professionals to establish and maintain a climate of mutual respect, dignity, diversity, ethical integrity and trust.			
7.2 Use knowledge of one's role and the roles of other health professionals to appropriately assess and address the needs of patients and populations served to optimize health and wellness.			
7.3 Participate in interprofessional teams to provide patient- and population-centered care that is safe, timely, efficient, effective and equitable.			

**Domain 8: Personal and Professional Development**

Demonstrate qualities required to sustain lifelong personal and professional growth.

Competency	Area for Improvement	Satisfactory	Proficient
8.1 Set learning and improvement goals. Identify and perform learning activities that address one's gaps in knowledge, skills, attitudes and abilities.			
8.2 Demonstrate healthy coping mechanisms to respond to stress; employ self-care strategies.			
8.3 Manage possible and actual conflicts between personal and professional responsibilities.			
8.4 Recognize that ambiguity is part of patient care and respond by utilizing appropriate resources in dealing with uncertainty.			

## Appendix F: Sample Patient Navigator Interview Questions

The following patient navigator interview questions were developed based on the Core Competencies for Non-Clinically Licensed Patient Navigators. Feel free to adapt and use any of the questions.

### Patient Care

What is your experience providing patient care?

Describe how you would conduct a patient assessment.

Can you provide an example of how you have identified resources for a patient based on their specific needs and health literacy?

In what ways would you support patients to help them participate in shared decision making?

### Knowledge for Practice

Have you had any formal training on medical and cancer terminology?

What resources do you most often refer to for evidence-based information for yourself?

How familiar are you with health insurance and how health care is financed?

Do you have any experience with quality improvement?

### Practice-Based Learning and Improvement

Give an example of how you have learned something on the job and used that information to make improvements to how you work.

Have you ever been involved in program development and/or evaluation?

Describe a time when you have incorporated feedback from a co-worker or patient into your work.

What types of information technology help you do your work more efficiently?

How do you track your activities with patients, including barriers, patient interactions and barrier resolution?

### Interpersonal and Communication Skills

How would you deal with an angry patient?

How would you be an effective liaison between patients and providers?

Describe a time when you've had a difficult conversation with a patient. How did you handle it?

What strategies do you think are important to help patients advocate for themselves?

How do you promote cultural and linguistically appropriate interactions with patients?

### Professionalism

How do you set boundaries to make sure you are staying within your scope of practice?

What would you do if another member of the health care team asked you to do something that was outside of your scope of practice, such as call a patient with test results or tell a patient that their treatment isn't working?

What role do you think patient navigators play on the health care team?

How do you build trust with patients?

Describe your organization and time management skills.

Describe a time when you used problem solving and critical thinking skills to help a patient.

How do you maintain patient confidentiality?

### **Systems-Based Practice**

If you had limited resources, such as public transportation fare, how would you prioritize who receives the resource?

If you noticed a challenge that many patients face and had an idea for how to address the challenge, what would you do?

### **Interprofessional Collaboration**

Describe your experience as part of a health care team. How did you handle conflict?

What are your professional development goals?

What professional development activities have you found most useful in the past?

Working with cancer patients can be emotionally challenging. What self-care or coping strategies do you use to make sure you do not burn out?

What would you do if your supervisor asked you to complete a task but did not provide enough detail about what to do?

## Appendix G: Example Focus Group Guide for Patient Navigation Networks

### **Purpose:**

The purpose of this focus group is to better understand what is most valuable to the Patient Navigation Network for future engagement.

### **Target Audience:**

The target audience for the Patient Navigation Network Focus Group is Patient Navigation Network collaborating sites. Navigators and supervisors that have been a part of the network at any time are invited to participate.

### **This focus group aims to include:**

- Six to ten participants
- Variation of sites providing navigation across the cancer care continuum: community health clinics, treatment facilities, Department of Health
- A diverse set of participants with regards to gender, race, ethnicity and age

### **Direction to Facilitator**

- Inform participants of the purpose and goal of the focus group
- Assure participants that their responses will remain confidential and de-identified (not linked to information that would identify them)
- Remind participants that their participation in the group is voluntary, with the option to withdraw at any time
- Confirm participants' permission to record the session and remind participants to avoid speaking over each other to make it possible to hear everyone's comments on the recording
- Remind participants that they will receive a \$X gift card for their time and participation in the focus group (NOTE: It is helpful to provide an incentive if you have the financial resources)
- Establish a time limit of approximately 90 minutes

### **Statement to Participants:**

The goal of this group is to engage you in a discussion of your experience as part of the Patient Navigation Network. The purpose is to understand your preferences for future engagement. During the focus group, you will be asked questions about your preference for ongoing professional training, resources and information sharing, preferences for how to support sustainability of navigation in your institution and data collection. No one will be quoted by name in any reports developed from this focus group. There are no "right" or "wrong" answers. We ask that you share your candid thoughts and that we all respect the perspective of other participants. As you know, we want you to share your opinions openly. This means that we all have to understand that this conversation is private. None of us should talk to others about what someone said in this room. We each need to believe that our statements are our own and will not be shared. Do we have an agreement and understanding of the confidentiality of this session?

There is limited time for each topic. You are encouraged to listen to the comments of others and allow time for others to speak. Your participation in this group is voluntary, with the

option to withdraw at any time. At this time, I'd like to confirm your permission to record the session. Is everyone comfortable with that? Please avoid speaking over each other to make it possible to hear everyone's comments on the recording. You will receive a \$X gift card for your time and participation today. We will conclude the session in approximately 90 minutes.

### **Content:**

Focus group discussion will center on the theme of engagement of the network as it relates to professional development, communication, sustainability of navigation, and data collection. The discussion will inform the following overarching questions:

1. How do you want to engage as a network?
2. What is the preferred format and content of ongoing professional training, resources and information sharing?
3. What would help sustain your positions and show the value of navigation to your institutions?
4. What would make data collection and sharing easier with the overall goal to show how navigators help reduce the burden of cancer?

### **Engagement**

1. Please tell me why the network is important to you. What do you most want to achieve with the network moving forward?
2. Let's talk a bit about the concept of a patient navigation network. What should membership in the patient navigation network mean?  
*Probes:* Should there be an application? Should there be membership criteria? If yes, what criteria? Should there be a leadership team or committee? Should there be a mission, affiliation, scope of activities, and priority population?
3. Please share your ideas on how to increase engagement with our network.
  - a. What else would be helpful to keep the navigators and sites engaged in the network?
  - b. How could we grow the communication and interaction among sites to foster a continued team approach to navigation of patients in the geographic area?
  - c. What other navigators should be invited to participate in the network?
  - d. What other organizations should be invited to participate in the network?
4. What is different about being part of the network versus navigating independently?
5. Please tell me what communication infrastructure looks like.
  - a. What are your preferences for format?
  - b. What are your preferences for content?
  - c. What communication would you like included?
  - d. What information is important to communicate?
  - e. How frequently do you prefer this communication?*Probe:* What is important to include: Resources for patients? Training and professional development opportunities? Blog? Listserv? Newsletter? Navigation Network website?

### **Professional Development**

Let's talk about regular meetings.

1. How is the content useable with your work with patients?
2. How could trainings better meet your needs?
3. How could trainings be more interactive for you?

4. Would you like networking time? What might that look like?
5. Please tell me what professional development format works best for you.  
*Probe:* What are the top preferences? Web-based trainings? Monthly in-person meetings? Quarterly in-person meetings? A mixture of web-based trainings and in-person meetings?

### **Evaluation**

Let's talk about what would be of value to track to show the city/state the value of patient navigation and sustain positions.

1. How do you currently track your productivity?  
*Probe:* Do you track in the EMR?, What do you track?, What do you have to show to your supervisors, division, organization, etc.?
2. What data would show the value of your position to your organization?
3. How important do you feel it is for us to work together to demonstrate shared outcomes for patient navigation?  
*Probe:* Would sites support working together to collect common measures to enable a city/state-wide report to stakeholders on navigation impact?

### **Wrap Up**

Are there any final comments or questions?

This concludes our focus group. Thank you for your time and input.

## Appendix H: Example Survey for Patient Navigation Networks

### Overall Impact

1. What do you think is most valuable about your participation in the Patient Navigation Network? (Select all that apply.)
  - a. Connection with other patient navigators
  - b. Sharing of resources and information
  - c. Interaction with expert speakers
  - d. Other (please specify: \_\_\_\_\_)
2. How successful do you believe the network has been in achieving its goals?
  - a. Very unsuccessful
  - b. Unsuccessful
  - c. Neutral
  - d. Successful
  - e. Very successful
3. How valuable do you think your supervisor finds your participation in the network?
  - a. Not valuable at all
  - b. Minimally valuable
  - c. Neutral
  - d. Somewhat valuable
  - e. Very valuable

### Meeting Structure

4. Please rate how helpful the current meeting format is:
  - a. Very unhelpful
  - b. Unhelpful
  - c. Neutral
  - d. Helpful
  - e. Very helpful
5. Please select the optimal day you would prefer for meetings.
  - a. Monday
  - b. Tuesday
  - c. Wednesday
  - d. Thursday
  - e. Friday
  - f. Saturday
6. Please select the optimal time you would prefer for meetings.
  - a. 9:00 am-11:00 am
  - b. 1:00 pm- 3:00 pm
  - c. 3:00 pm- 5:00 pm
7. Which do you feel is the MOST compelling reason for you to attend meetings?
  - a. Topic of the training will help me assist my patients
  - b. Topic of the training will benefit my professional development
  - c. Networking opportunities with other navigators

- d. A well-respected speaker will be presenting on the topic
  - e. I do not plan to attend Patient Navigation Network trainings in 20XX
  - f. Other (please specify)
8. Do you prefer network meetings to be:
- a. In person
  - b. Online (E-learning/webinars)
  - c. Blended online and in person
  - d. Other (please specify: \_\_\_\_\_)
9. How often should meetings take place:
- a. Weekly
  - b. Monthly
  - c. Quarterly
  - d. Yearly
10. Would you like time at the beginning or end of meetings to have opportunities for each navigator to share updates or resources at their respective organizations?
- a. Yes
  - b. No
11. Please provide feedback on the location of the meetings. Which do you think should be the TOP consideration when choosing the location for the monthly meetings?
- a. Convenience to public transportation
  - b. Availability of nearby parking
  - c. Other (please specify: \_\_\_\_\_)
12. I would like more training in the following area(s): Please choose all that apply
- |                                   |                                            |
|-----------------------------------|--------------------------------------------|
| a. Communication Techniques       | n. Health Disparities                      |
| b. Care Coordination              | o. Human Development                       |
| c. Reductions in Barriers         | p. Resources                               |
| d. Health Promotion               | q. Motivational Interviewing (MI)          |
| e. Screening and Early Detection  | r. Health Literacy                         |
| f. Palliative Care                | s. Facilitation Skills                     |
| g. Disease Management             | t. Health Behavior Change Theories         |
| h. Disease and Illness Background | u. Community Assessment                    |
| i. Social Determinants of Health  | v. Focus Groups                            |
| j. Self-Care                      | w. Program Evaluation                      |
| k. Professional Boundaries        | x. Other                                   |
| l. Ethics                         | y. None, I feel I have sufficient training |
| m. Cross Cultural Communication   |                                            |
13. Please describe the other area(s) in which you would like more information or training:

### Communication Preferences

14. What are your preferences for the format of communication within the network:
- a. Emails

- b. Newsletters
- c. Website
- d. Listserv
- e. Blog

15. How frequently would you like to receive communication within the network?

- a. Daily
- b. Weekly
- c. Monthly
- d. Quarterly
- e. Yearly