

# Catalyzing Patient-Centered Care

Start Where You  
Are and Share  
What You Know



Over the last decade, patient-centered care has begun to gather momentum spurred on by a series of commissioned reports, insurance reform, and new accreditation standards. The Institute of Medicine (IOM) has issued several reports on quality and cancer care, including the most recent report, *Delivering High Quality Cancer Care: Charting a New Course for a System in Crisis*.<sup>1</sup> This 2013 report espouses a conceptual framework that includes patient engagement at the center of a quality cancer care system. Other IOM reports have focused on the needs of post-treatment cancer survivors<sup>2</sup> and the importance of caring for the whole patient and not simply treating the disease.<sup>3</sup>

With the passage of the Affordable Care Act (ACA) in March 2010, patients benefit from expanded access to care, increased affordability of insurance, new patient protections, elevated quality measures, and new funding for patient-centered research. The ACA established both the Center for Medicare and Medicaid Innovation, which tests new payment models that elevate quality of service over volume of procedures, and the Patient-Centered Outcomes Research Institute (PCORI), which includes patients as key stakeholders in research and focuses on outcomes that are most important to patients.

Finally, the American College of Surgeons' Commission on Cancer (CoC) established new patient-centered standards to be phased in by 2015<sup>4</sup> for its more than 1,500 accredited programs that treat more than 70 percent of newly diagnosed cancer patients in the U.S.<sup>5</sup> These standards include establishing a patient navigation process (3.1), implementing psychosocial distress screening (3.2), and providing survivorship care plans to patients completing treatment for cancer (3.3).

In 2013, in collaboration with its clinical partners, the George Washington (GW) Medical Faculty Associates and the GW Hospital, the GW Cancer Institute:

- Expanded and enhanced its patient navigation program
- Established a distress screening process
- Continued to refine its survivorship services
- Expanded technical support to other institutions to catalyze patient-centered care practices regionally and nationally.

### Navigation Across the Continuum

CoC Standard 3.1: Patient Navigation Process requires that accredited institutions develop and implement a process to address disparities and barriers to care experienced by cancer patients and that is responsive to a community needs assessment. Patient navigation refers to individualized assistance offered to patients, families, and caregivers to remove barriers to accessing and completing cancer screening, diagnosis, treatment, and supportive care.

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The GW Cancer Institute used local research findings for its community needs assessment. Drawing from research that showed that diagnostic time was reduced by an average of 17 days for women in the District of Columbia at-risk for breast cancer who received navigation versus women who did not receive navigation,<sup>6</sup> the GW Cancer Institute spearheaded a Citywide Patient Navigation Network (CPNN) to provide a safety net for those at risk for cancer or undergoing treatment in the DC area. Under the auspices of CPNN, primary care clinics, community-based organizations, and cancer centers in the region collaborated to remove 26,259 barriers to healthcare experienced by 7,309 individuals at various points along the cancer continuum from August 2010 through July 2013. Approximately 84 percent of individuals served by CPNN were

**Figure 1. Sample Evaluation Tool**

<b>CPNN PATIENT INTAKE FORM</b>	CPNN Site Location:					Date of Patient Encounter:			
	Navigator Name:			Patient ID:		Date Submitted:			
Circle One:	First Navigation Encounter					Continuing Navigation			
<b>FILL OUT FOR EVERY PATIENT ENCOUNTER – PATIENT DEMOGRAPHICS</b> (circle to indicate choices)									
<b>GENDER &amp; RESIDENCY</b>	Male	Female	Transgender	Maryland	Virginia	Other: _____		Washington, DC	
<b>RACE &amp; ETHNICITY</b>	Black	African	Hispanic	White	American Indian	Pacific Islander	Asian	Ward 1	Ward 2
<b>POINT OF ENTRY INTO CPNN</b>	Outreach	Screening	Abnormal Finding	Cancer Diagnosis	Treatment	Survivorship	Receiving Palliative	Ward 3	Ward 4
<b>RISK ASSESSMENT AREA</b>	Breast	Prostate	Colorectal	Cervical	Lung	Other: _____		Ward 5	Ward 6
<b>AGE RANGE</b>	18–29	30–39	40–49	50–64	65+	Tobacco User Yes No		Ward 7	Ward 8
<b>SEXUAL ORIENTATION</b>	Lesbian	Gay	Bisexual	Queer/Questioning	Heterosexual	Referred to DC Quitline Yes No		Type: Cigarette/Pipe/Snuff	
<b>INSURANCE HELD &amp; LAST PCP VISIT</b>	Uninsured	Uninsured, Navigated to Insurance	Fee for Service	Medicaid	Medicare	Employer/Private/Commercial Specify: _____		Seen Past 12 Months Yes No	

<b>TIME INTERVALS:</b> Indicate the following time intervals as you know them. Do not indicate intervals prior to your first navigation encounter or after your last encounter with the patient.	Screening to Diagnosis	Less than 30 days	30–60 days	More than 60 days	Unknown/Prior to First Navigation Encounter	
	Diagnosis to Treatment	Less than 30 days	30–60 days	More than 60 days	Unknown/Prior to First Navigation Encounter	
	Completed Treatment?	Yes	No	Received survivorship information?	Yes	No

<b>TYPE &amp; NUMBER OF BARRIER(S) PATIENT IS FACING</b>	<b>NUMBER OF REFERRALS</b>		<b>WHO HELPED ADDRESS/RESOLVE THE BARRIER?</b>	
<b>BARRIER TYPE</b> (include total patients this period)	Number of Referrals made for service	Number of Navigators who helped in overcoming the barrier	Which Navigator/CPNN site(s) helped you overcome the barrier? <i>List all that apply</i>	Which non-CPNN Agency did you refer for service (i.e. Medicaid, METRO, etc.)? In which state is the agency located?
1. Transportation				
2. Housing				
3. Social/Practical (i.e. Support Group, Food)				
4. Language Barrier/Interpreter needed				
5. Literacy				
6. Dependent (child or adult) care issues				
7. Location of healthcare facility				
8. Financial: insurance, high co-pays, rent				
9. Employment Issues				
10. Communication concerns with medical personnel				
11. Fear or negative perceptions				
12. Patient disability				
13. System problems with scheduling care				
14. Anxiety because of discrimination/stigma				
15. Other, specify: _____				

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## The GW Cancer Institute collaborates with its clinical affiliates to provide patient navigation services across the cancer continuum to ensure timely access to care for patients.

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racial or ethnic minorities, of whom more than 50 percent were African American or African and nearly 32 percent were Latino individuals. Top barriers included:

- Financial barriers (16 percent)
- Social and practical support concerns, such as the need for a support group or help buying food (16 percent)
- System problems with scheduling care (14 percent)
- Language barriers (12 percent).

Additional obstacles to care include transportation, geographic location of healthcare facilities, fear and communication barriers, and employment concerns. Figure 1, left, is an example of an intake form that can be used to assess navigation barriers.

The GW Cancer Institute collaborates with its clinical affiliates to provide patient navigation services across the cancer continuum to ensure timely access to care for patients. The team includes a navigation supervisor, three non-clinically licensed patient navigators, two nurse navigators, one social worker, a research assistant, and rotating practicum students in public health.

Patient navigators without a clinical license focus on eliminating structural and logistical barriers to care. The most common non-clinical navigator interventions include language support, helping eligible patients access insurance or co-pay programs, scheduling necessary follow-up appointments, social and practical support, and transportation assistance.

Two navigators in radiology assist all patients who have an abnormal finding in the breast imaging and intervention center. One navigator specializes in support for Spanish-speaking patients and resolution of logistical barriers to fast-track patients to diagnosis. The navigators in radiology work with navigators in breast surgery and radiation oncology to ensure access to timely biopsy, surgery, and radiation treatments.

A nurse navigator provides clinical education for those at high-risk for breast cancer and diagnosed patients.

A licensed clinical social worker based in hematology and oncology provides support for patients undergoing chemotherapy. The social worker also mentors the navigators, counsels patients in high distress, and coordinates referrals to a specialized survivorship psychiatric services program.

The GW Cancer Institute leverages its educational infrastructure to further support the navigation program. Public health students are provided with concrete projects to assist the navigation team in making quality improvements. In addition, a half-

time research assistant coordinates technical support for CPNN and assists with data analysis and evaluation improvements.

In 2013 the navigation team prioritized three areas for improvement. First, the team conducted a new needs assessment to better understand the population it was serving. Second, the team mapped the patient experience across the breast cancer continuum to identify quality improvements. Third, the team researched options for improved efficiency of data capture and identified key metrics for a pilot database.

The needs assessment compared the demographics of navigated patients to the demographics of all patients who are treated at GW based on cancer registry data. The assessment outlined top needs of patients navigated and highlighted areas where important data was missing due to data infrastructure limitations. Findings from the assessment showed that the GW navigators are reaching the neediest population of patients. Of those navigated, 73.8 percent were minorities, favorably comparing to the 48.5 percent minorities noted in the registry data. Navigators also reach a large number of uninsured and Medicaid patients. Nearly 40 percent of patients receiving navigation were uninsured or on Medicaid. The needs assessment also found that while the breast cancer navigation program at GW is strong, work remains to be done to identify those non-breast cancer patients at high-risk of falling through the cracks.

One key limitation of the data is the difference between the comparators: many individuals at-risk for cancer who receive navigation to obtain diagnostic resolution are not captured in the cancer registry data because they are ultimately resolved as benign cases. The registry system also only captures individuals who have received some portion of their care at the GW Hospital, excluding patients who have only received outpatient services. However, the needs assessment was important to highlight areas to improve data capture and expand services for patients in need who are cared for in other clinical departments.

The navigation team also mapped the patient experience across the breast care continuum. A number of quality improvement initiatives resulted. These include:

- Educating community clinics on accurate Current Procedural Terminology (CPT) codes for screening referrals
- Drafting a navigator script to introduce the patient navigator prior to the clinical appointment to proactively assess any barriers to care
- Calling patients lost during follow-up who were recommended for additional imaging



Front (L to R):  
 Heather Kapp, Diana Garcia,  
 Eva Ruiz, Monica Dreyer,  
 and Mandi Pratt-Chapman.  
 Back (L to R):  
 Elizabeth Hatcher, Jennifer  
 Bires, Leshia Hansen,  
 Anne Willis, Megan Matheny,  
 Margaret Chapman, and  
 Elisabeth Reed.

- For biopsied patients, making the next appointment on the same day of biopsy
- Ensuring required authorizations are attained prior to breast surgery
- Tracking patients and following up with those lost during follow-up after simulation planning in radiation oncology
- Sending appointment reminder cards and directly referring eligible patients to survivorship services.

Additionally, the navigation team is exploring the feasibility of a navigation steering committee to increase referrals from clinical areas other than breast.

Finally, the navigation team worked collaboratively to identify key metrics important in showing the value of patient navigation at GW.

Since August 2010, the navigators have tracked demographics, barriers to care, and resolution of barriers on an Excel form and reported aggregate numbers of patients assisted on a quarterly basis to provide information to funders on program impact. A major limitation of this method of data capture is double or triple counting patients if the patient moves across several clinical departments and is assisted by more than one navigator in the process. In 2013 the navigation team added a navigation note to the electronic medical record (EMR). The standardized note provides clear, concise information on navigator-initiated interventions that eliminated barriers to care for that patient. The note improves communication, assists with care coordina-

tion, and provides official documentation to clinicians to raise awareness regarding patients' unique concerns. It may also increase referrals due to greater awareness of patient needs. However, the EMR does not compile reports and thus cannot be used to evaluate the program.

Currently, GW is working with its legal and security advisors to implement a navigation database to improve accuracy and efficiency of data capture, increase information sharing, and maintain patient privacy in the year ahead. The database will also expand health equity data captured, enhance barrier tracking, and include a patient satisfaction survey to contribute to ongoing needs assessment, evaluation, and quality improvements.

### **Distress Screening**

According to the National Cancer Institute (NCI), cancer patients' suicide risk can be two to ten times that of the general population. Some studies indicate that suicidal thoughts are common even if patients do not commit suicide, and actual suicide may go underreported in this population. Patients with head and neck, pharyngeal, and lung cancer are at higher risk for depression, which may be linked to heavy alcohol and/or tobacco use. HIV-positive patients with Kaposi Sarcoma are also at higher risk for depression. Other risk factors include advanced disease, poor prognosis, or uncontrolled pain.<sup>7</sup>

Even if cancer patients are not suicidal, many patients can experience significant short- or long-term distress due to their cancer and/or concurrent factors. Distress refers to emotional,

mental, social, or spiritual suffering, and might include anxiety, depression, or feelings of sadness, isolation, or vulnerability.<sup>8</sup> Distress can impact a patient's ability to complete the diagnosis or treatment process, and may decrease overall quality of life.

CoC Standard 3.2, Psychosocial Distress Screening, requires that accredited cancer programs establish a process for integrating and monitoring distress screening and the provision of psychosocial care either on-site or by referral. The CoC is flexible on when and how this screening is done, but recommends that it occur at a "pivotal" visit (broadly defined as diagnosis, pre- or post-surgical visits, pre-chemotherapy, routine radiation oncology visit, post-chemotherapy, or transition off-treatment) and states a preference for using validated screening tools.

To comply with this standard, the GW Cancer Institute brought together nurses, social workers, and patient navigators to create a distress screening procedure and drafted the distress screening policy discussed below. We selected the National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) as a simple, one-page, validated tool to measure distress in our cancer patient population. The NCCN DT includes a scale from zero (no distress) to ten (extreme distress), as well as a problem checklist that includes practical barriers, family problems, emotional problems, spiritual concerns, and physical problems. The DT is presented to patients on their initial visit in infusion, radiation oncology, and/or medical oncology and prior to breast surgery with a letter explaining the tool. The completed tool is reviewed by a nurse, social worker, or patient navigator.

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Based on the results of the screening, referrals are made to staff and resources. Patients in low distress (self-rating of 0-3), are given a new patient information packet, including a list of support groups and educational classes. Patients are also given contact information for the social worker or the psychosocial care team in the event distress arises later in treatment.

For patients in moderate distress (self-rating of 4-6), the staff person reviewing the tool contacts the patient within 72 hours for further evaluation to confirm presence of physical, psychological, social, spiritual, and/or financial concerns. Resources and

referrals are given to meet the patient's needs, which could include a therapist referral.

For patients in high distress (self-rating of 7-10), staff conducts an assessment within 24 hours to confirm the presence of physical, psychological, social, spiritual, and/or financial needs. Resources and treatment are provided to meet the patient's self-identified needs, which can include referrals for two to three therapists to provide options to the patient if therapeutic support is indicated.

For all patients—regardless of the level of distress—practical concerns are referred to the navigation team. The patient is referred to social work, financial counseling, spiritual care, palliative care, or other mental health specialists, depending on their self-reported area of need. The treating oncologist is alerted via the EMR chart note of moderate or high distress. If the cause of distress is primarily physical, the patient is triaged back to their physician. If a patient is deemed suicidal, staff contact psychiatry immediately and if psychiatry cannot consult with the patient right away, security or 911 are called. The patient cannot leave the cancer center without being seen by an advanced practice mental health professional and is not left alone. All patients, again regardless of distress level, are encouraged to contact staff if distress escalates to uncomfortable levels or if additional support or services are needed.

The completed DT is scanned into the patient's EMR and the staff person screening the patient is responsible for sending referrals to the navigation team or to other providers as indicated. Referral or provision of care is also documented in the EMR by the individual screening the patient to facilitate integrated, high-quality care. Follow-up care is documented by the staff member providing the care.

These processes were spelled out in the distress policy presented to the cancer committee, which approved the policy in 2013. Screening was implemented first in the division of hematology and oncology, and then in the breast care center. Currently, we are working to improve screening in radiation oncology and to initiate screening in other clinical areas. Some oncologists have begun to document distress as the seventh vital sign, and a working group is advocating for this documentation as a standard practice for our hematologists and oncologists.

GW continues to evaluate and refine its distress screening process. Based on research stating that the DT is not as accurate in assessing depression as anxiety, the team is considering the inclusion of two additional questions to more accurately screen for depression:<sup>9</sup>

- In the last two weeks, have you experienced little interest or pleasure in doing things?
- In the last two weeks, have you felt down, depressed, or hopeless?

For both questions, patients can answer: not at all (worth zero)  
*(continued on page 38)*

## Figure 2. MFA-GWCI Survivorship Care Plan

Summary of Cancer Treatment and Follow-Up Plan

Name \_\_\_\_\_

DOB \_\_\_\_\_

### TREATMENT SUMMARY

Oncologist: \_\_\_\_\_

Surgeon: \_\_\_\_\_

Radiation Oncologist: \_\_\_\_\_

Internist: \_\_\_\_\_

Diagnosis/Staging/Age: \_\_\_\_\_

Pertinent Family History/Genetics: \_\_\_\_\_

### SURGERY

Procedure:	Date:

### CHEMOTHERAPY/BIOOTHERAPY

Regimen:		Dates:	
Drug Name	Dose	Dose Reduction	Cycles

### RADIATION THERAPY

Length (fractions)	Field	Total Dose	Dates

### HORMONE THERAPY

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### FOLLOW-UP PLAN

Potential Late Effects	Screening Recommendations*
1. Cancer Recurrence	

\*Screening recommendations adapted from the National Comprehensive Cancer Network, NCCN Guidelines Version \_\_\_\_\_ for Invasive \_\_\_\_\_ Cancer.

## MFA-GWCI Survivorship Care Plan

Summary of Cancer Treatment and Follow-Up Plan *(continued)*

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### HEALTH MAINTENANCE

- ✓ Physical examinations by internist, annual
- ✓ Colonoscopy, per gastroenterologist
- ✓ Routine self breast exams, monthly
- ✓ Cancer survivorship support through post-treatment breast cancer support group
- ✓ Other

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### HEALTHY LIFESTYLE RECOMMENDATIONS

- ✓ **DIET** – Eat a heart healthy diet low in salt, fat, red meat, and sugar and high in fresh fruits, vegetables, and whole grains. Follow individual recommendations provided by dietitian.
- ✓ **ALCOHOL** – Limit your alcohol intake to 2 drinks a week.
- ✓ **EXERCISE** – Get 30 minutes of moderate exercise most days of the week or enroll in the GW TACfit program for individual physical activity assessment and plan.

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### SYMPTOMS TO WATCH FOR

It is important for you and your providers to understand the potential late effects and risks of your cancer treatment.

If progressive and/or persistent report these signs and symptoms to your practitioner:

*(Symptoms listed depending on the cancer type)*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### POTENTIAL LATE EFFECTS AND RISKS OF ALL CANCER TREATMENTS

The late side effects of cancer treatment one may develop months to years after treatment depends on which treatment(s) were received.

**Surgery:** *(specific side effects listed depending on the location and extent of surgery)*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Radiation:** *(specific side effects listed depending on the location and dose of radiation)*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Hormone Therapy:** *(side effects of the particular hormonal therapy are listed)*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

This Survivorship Care Plan was prepared by \_\_\_\_\_, provided to the patient and sent out to the providers listed on \_\_\_\_\_.

(continued from page 35)

points), several days (1 point), more than half the days (2 points), or nearly every day (3 points). Patients who score a total of at least 3 points on both questions are considered to be at-risk for having depression.

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**In 2010 the GW Cancer Institute, in collaboration with the Children's National Medical Center, the GW Medical Faculty Associates, and the GW Hospital, established its first survivorship clinic, focusing on adult survivors of pediatric cancer.**

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### **Survivorship Care**

CoC Standard 3.3, Survivorship Care Planning, requires the cancer committee to develop and implement a process to provide survivorship care plans, including a treatment summary and follow-up plan, to patients completing cancer treatment.

In 2010 the GW Cancer Institute, in collaboration with the Children's National Medical Center, the GW Medical Faculty Associates, and the GW Hospital, established its first survivorship clinic, focusing on adult survivors of pediatric cancer.

In 2012 a second multidisciplinary clinic was established to provide comprehensive care for adult-onset cancer survivors. The clinic is housed in the division of internal medicine and coordinated by an oncology nurse practitioner (NP). Survivors may be referred to the clinic at any point following active cancer treatment. The survivorship nurse navigator conducts patient intake via phone, and the NP prepares the survivorship care plan (see Figure 2, pages 36-37). The survivor benefits from consultation with the NP, an internal medicine physician, and a registered dietitian. During this clinical visit, the NP provides education regarding the survivorship care plan, the internist addresses management of potential medical concerns, and the dietitian reviews the patient's diet and health behaviors. The survivor also meets with the nurse-credentialed survivorship navigator during the visit. The navigator assesses the patient for resource needs, and is available for the patient to contact after the visit.

Survivors may also be referred to specialists as needed, including free, time-limited psychiatric services offered on-site or by referral and an individual exercise assessment and plan by GW's Department of Exercise Science.

The GW Cancer Institute, with its clinical partners, is still

determining the best method to expand provision of survivorship care plans to a greater number of patients to comply with the CoC standard. As part of the navigation team's patient experience mapping process, referral to survivorship services was identified as a gap. New processes for referring patients to the survivorship clinic are now being implemented. Future steps also include engaging clinical champions to pilot new approaches to providing survivorship care plans.

### **Finding Your Patient Focus**

The GW Cancer Institute provides technical support to other programs, leveraging lessons learned and best practices across the country. In 2009 the GW Cancer Institute Center for the Advancement of Cancer Survivorship, Navigation, and Policy was launched. Through the center, we have trained nearly 500 healthcare professionals in live trainings focused on patient-centered program development. In April 2013 we launched a free webinar series that provides monthly educational opportunities for healthcare professionals. Content for the webinar series has focused on assessing need for patient-centered programs, case studies, survivorship resources, survivorship care planning practices, and the importance of cancer rehabilitation. In 2014 the GW Cancer Institute will create an online version of its highly reputed *Executive Training in Navigation and Survivorship* to assist institutions aiming to establish patient-centered care practices.

As part of the National Cancer Survivorship Resource Center, a collaboration between the American Cancer Society and the GW Cancer Institute funded by the Centers for Disease Control cooperative agreement #1U55DP003054, the GW Cancer Institute has developed a free Cancer Survivorship e-Learning series for primary care providers available online at: [www.cancersurvivorshipcentereducation.org](http://www.cancersurvivorshipcentereducation.org). Modules include:

- The Current State of Survivorship Care and the Role of Primary Care Providers
- Late Effects of Cancer and its Treatments: Managing Comorbidities and Coordinating with Specialty Providers
- Late Effects of Cancer and its Treatment: Meeting the Psychosocial Health Care Needs of Survivors
- The Importance of Prevention in Cancer Survivorship: Empowering Survivors to Live Well
- A Team Approach: Survivorship Care Coordination.

A free *Guide for Delivering Quality Survivorship Care* is available on the same website to support healthcare professionals and program leaders through assessment, planning, implementation, and evaluation of their survivorship program.

The GW Cancer Institute also conducts research to elevate patient-centered care practices. In 2013 PCORI provided funding to the GW Cancer Institute and the GW School of

Public Health and Health Services to evaluate cancer survivorship programs across the country. Key collaborators on the project include the CoC, LIVESTRONG, the Cancer Support Community, and the American Cancer Society. The research team will create a patient-prioritized measure for quality survivorship care and evaluate programs based on outcomes of importance to patients.

The GW Cancer Institute is also collaborating with the Association for Community Cancer Centers, the National Association of Social Work, the Association of Oncology Social Work, the Oncology Nursing Society, and the Association of Oncology Nurse Navigators to delineate roles and responsibilities of patient navigators, sometimes referred to as lay navigators, as compared to community health workers and nurse or social worker navigators. The project will result in identified competency domains for non-clinically-licensed patient navigators and a free online training program. Results from both research projects will inform patient-centered care practices across the country.

The shift from volume to value is here to stay. With a trend toward more engaged and active patients, there is widespread recognition of the need for patient-centered care. Oncology teams have an opportunity to be part of the solution for a more effective care system by responding to the call for improved quality and greater patient engagement in care. The GW Cancer Institute remains committed to catalyzing patient-centered care by engaging patients, improving quality, and sharing what we know with other programs to benefit all patients. 

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