

Navigating Patients Across The Care & Treatment Continuum Winter 2024 Impact Report







Thank you for helping us end cancer as we know it, for everyone.

Dear Partners,

The American Cancer Society (ACS) is deeply grateful for your visionary leadership and ongoing partnership. Because of your support, our Patient Navigation Initiative was made possible. Today, we are sharing updates on the program to highlight how we are enhancing and innovating existing institutional oncology patient navigation processes, policies, and systems.

Your generous support has opened pathways to addressing barriers, gaps, and challenges for individuals with cancer, their caregivers, and families, especially within marginalized communities. We are all so proud of this work and appreciate your leadership in this initiative. We look forward to continuing our partnership to develop more innovative and impactful navigation strategies/solutions and pathways for navigation expansion and long-term sustainability, leading health systems toward an integrated approach for seamless patient-centered experiences from pre-diagnosis through survivorship.

Thank you for all you do to support our mission.

Your American Cancer Society



"ACS support also has been critical to our ability to design and implement a risk stratified, nurse-integrated remote symptom monitoring program for oncology patients at UNC. Also important to note is that the ACS support enabled the building of bridges between our academic cancer center and the health system. Members of the Oncology Central Navigation program have been invited to and are now actively working with staff at UNC's Lineberger Comprehensive Cancer Center to develop infrastructure for researchers wanting to study oncology navigation innovation. This important work will provide a tool kit for researchers wanting to conduct comparative effectiveness and implementation-related research around oncology navigation services."

- UNC Lineberger project team member



Patient Navigation Initiative

The ACS Patient Navigation Initiative program is a component of the Society's commitment to **enhancing oncology patient navigation** and addressing barriers to individualized, timely, and equitable access to care for cancer patients and their families. The project goal is to advance high-quality cancer care through capacity building and support for innovative, sustainable models of oncology patient navigation.

Throughout the project, the American Cancer Society will **support the health system grantees through funding, feedback, and convenings** as they address challenges and opportunities to strengthen their programs and ensure sustainability in navigation.

Capacity Building Grants	 Grants to 20 health systems to expand, innovate and improve their current navigation
Grantee Learning Community	•Community to provide technical assistance and best practices
Webinar Series	 Series to expand the reach of ACS capacity-building work beyond our grantees to systems across US

At the end of 30 months, ACS will **utilize the learnings and conclusions from the grantee projects to generate best practices and additional findings** that can be disseminated to the larger oncology community and **support the successful development of future oncology navigation programs** and policy objectives.

Grantee Project Timeline



departments and system clinics



Health System Grantees and Area of Focus

Because of your support, ACS funded **20 grantee projects** with the highest scalability, replication, and likelihood for advancing high-quality cancer care through navigation. Grantees chose a specific population of focus, shown below, for their navigation projects. Each grantee meets the following criteria:

- National Cancer Institute designated cancer program and/or Commission on Cancer accredited program
- Minimum annual analytical oncology caseload of 1,000 or CoC accredited Safety Net Hospital with smaller analytical caseload
- At least 25% health system's patient population Uninsured, on Medicaid, or are classified as Medicare only



Navigation Capacity-Building Grantee	Population of Focus
Boston Medical Center	Breast, lung, GI, Head & neck cancer patients
City of Hope – Los Angeles	All navigated cancer patients
Fred Hutchinson Cancer Center - Seattle	Hematology patients (Spanish-speaking)
Harris Health System - Houston	Lung cancer patients
Harold C. Simmons Comprehensive Cancer Center, UT Southwestern - Dallas	Cancer patients in clinical trials (underserved)
HIMA San Pablo Oncologico-Caguas – Puerto Rico	Breast, colorectal, lung/bronchus, pediatric cancer patients (99% Hispanic)
Huntsman Cancer Institute at the University of Utah	Rural cancer patients (includes 18 trial nations)
Markey Cancer Center, University of Kentucky	Socially disadvantaged cancer patients
Montefiore Einstein Cancer Center – Bronx	Locally advanced lung, gastroesophageal, rectal, pancreatic cancer patients
Rush University Medical Center - Chicago	Socially disadvantaged cancer patients (in focus neighborhoods)
Stanford Cancer Institute	Socially disadvantaged / minority cancer patients
Stephenson Cancer Center, University of Oklahoma – Oklahoma City	Native American cancer patients
University of Alabama at Birmingham	All navigated cancer patients
University of Chicago Medicine	All navigated cancer patients (underserved)
University of Colorado-Denver	All navigated cancer patients
University of New Mexico Comprehensive Cancer Center - Albuquerque	All navigated cancer patients
University of North Carolina at Chapel Hill	Hematologic and GI cancer patients
University of Southern California	Breast, lung, sarcoma cancer patients (socially disadvantaged)
University of Texas Health – San Antonio	All navigated cancer patients (underserved)
Virginia Commonwealth University Massey Cancer Center	All navigated cancer patients (underserved)



Grantee Data Collection

During the project implementation period (January 1, 2023, to December 31, 2024), grantees report aggregate patient demographics and data relevant to their specific aims. Reports are submitted twice yearly and include core metrics based on Standardized Evidence-Based Oncology Navigation Metrics, codeveloped by the Academy of Oncology Nurse and Patient Navigators and American Cancer Society.

The July 2024 collection was the third reporting of all required demographics and metrics. From January to end of June, grantees have continued to make progress toward collecting more complete, accurate data for all metrics. 19 of 20 grantees submitted at least six of the seven required core metrics.



Year 2 Interim Metrics (January 1, 2024 to June 30, 2024)

 Navigation Caseload 15K+ new individuals navigated 	All grantees successfully reported a navigation caseload.
2) No-Show Rate Rates ranging from 0% - 25%	Grantees continue to refine the process for calculating the no-show rate. Grantees are beginning to use the data to document decreases in no-shows, specifically for navigated patients. 7 of 20 sites demonstrated a decreased no- show rate from the previous reporting period.
3) Psychosocial Support & Assessment	All 19 grantees submitted Psychosocial Support and Assessment data. Nine sites were able to report screening rates, which ranged from 40% to 100%. Grantees are developing new processes for psychosocial screening. For example, one grantee implemented a new system for conducting psychosocial support and assessment through the Patient and Family Support (social work) team, resulting in a much higher rate of distress screenings.
4) Barriers to Care Top 3 Barriers Emotional concerns Financial concerns Transportation	All grantees submitted complete Barriers to Care data, which they captured in various ways, including surveys, focus groups, internal discussion and observation and notes documented by the patient navigator. Some grantees noted that the assessment is now integrated within patient interaction data in EPIC. Two grantees expanded the scope by collecting and reporting more than 3 barriers and even listing sub-barriers. Collecting more details can help navigation programs tailor their responses to individual patient needs.



Grantee Data Collection (Cont.)

5) Treatment Compliance

7 sites improved their treatment compliance rate.

Of the 7 required core metrics, this had the most variability in metric definition among grantees. Several grantees revised or refined their definitions for this metric. For example, one grantee chose a sub-population to focus on for this metric, collecting and reporting data on patients diagnosed with locally advanced cervical cancer (stages II and III). Working with their informatics team they identified these patients and determined if their treatment compliance was concordant with guidelines.

6) Diagnosis to Initial Treatment

8% reduction in median average number of days from diagnosis to treatment. **17 sites were able to submit complete data for this metric.** Data collection improved for several grantees. For example, one grantee was able to decrease the average number of days from diagnosis to treatment, by more than **30 days**, bringing it closer to the median average. Another grantee narrowed their population focus to new, navigated patients with breast, cervical, colorectal and lung cancer diagnoses for whom the navigation cycle began during this reporting period. Data analysis showed that their average days from diagnosis to treatment for this population has **decreased** slightly over the grant period.

7) Clinical Trials Education

175% increase in patients educated

Several grantees did not collect data on clinical trials education as it is not part of their navigators' scope of work. For grantees who did collect the data, it is leading to an important culture shift, where ALL patients are proactively educated about trials. **14 grantees** were able to educate **1,415 patients** about clinical trials during this reporting period.

8) Clinical Trials Referral

174 patients were referred to clinical trials.

6 of 20 grantees submitted data for this optional metric. While clinical trial navigators do refer patients to trials, it is not within the presently defined role of most patient navigators. There is a clear need for specialized navigation to reduce disparities in clinical trial enrollment. Currently, one project has a defined clinical trials navigator role.







Addressing Latinx CANcer Care Equity - Program for Long-term **United Skills-building (ALCANCE-PLUS)**

The ALCANCE-PLUS project builds upon the Addressing Latinx CANcer Care Equity (ALCANCE) initiative launched in 2021. ALCANCE is a patient navigation (PN) program that integrates bilingual community health workers into primary and oncology care in Monterey County, an agricultural community comprised of 60% foreign-born Latinx, Spanish-speaking populations. ALCANCE-PLUS aims to overcome identified gaps that remain in addressing the needs of low-income and minority patients after cancer diagnosis and create a sustainable, long-standing PN approach to address ongoing cancer care disparities in Monterey County. Success of the enhanced program will ensure equitable delivery of high-quality cancer care for the county's low-income and minority populations.

Strategies

- Train community health workers on various aspects of cancer care delivery
- Deliver PN services to cancer patients at Pacific Cancer Center in Monterey County
- Engage patients in advance care planning and proactive symptom screening
- Engage patients in culturally tailored, language-concordant precision medicine education
- Ensure access to free, culturally, and medically tailored food for patients undergoing systemic cancer treatment
- Enhance community capacity throughout the county

Successes

Patient Services

- Services actively implemented with patients at Pacific Cancer Care including:
 - Advanced care planning
 - ٠ Symptom management
 - Goals of care discussions

Training and Education for Community Health Workers

- Implemented training for community health workers on advanced care planning, goals of care, symptom management.
- Hosted several training sessions open to community health workers from various institutions across the country participate.

Culturally Tailored Resource Creation

Developed bilingual and culturally tailored materials including animated videos, flyers describing community health worker services, three-page handout explaining targeted therapy, infographics on tumor marker testing, advanced care planning, symptom management, and goals of care.

" Adding community health worker navigators as members of the care team allowed us to address unmet needs of patients like food insecurity and advanced care planning that have a direct impact on patient outcomes and satisfaction."

ALCANCE-PLUS Project Team





Patient Navigation Model Expansion at University of Chicago

The University of Chicago Medical Center (UCM)/University of Chicago Comprehensive Cancer Center (UCCCC) serves a high proportion of historically underserved cancer patients including non-white patients (43% Black, 6.2% Hispanic, 2.8% Asian) and those with public insurance options (Medicare 44%, Medicaid 23%). At present, UCM/UCCCC provides patient navigation (PN) services at two locations within its health system.

There is a need to reduce fragmentation and expand the existing PN model across the enterprise to better meet the needs of more vulnerable patients during their cancer journey. The goal of the improved PN program is to provide easily accessible, integrated navigation services across the UCM/UCCCC enterprise. This new design will help reduce barriers to achievable cancer outcomes and increase access to cancer care services to produce equitable experiences for all patients.

Strategies

UCM/UCCCC's navigation improvement strategy for the project centers on the needs of its financial and racially diverse cancer patient population. The strategy employs a three-pronged approach:

- Operational navigation management
- Digital patient experience
- Community engagement

To execute this strategy, the project leadership has brought together two teams:

- A multi-disciplinary project team including oncology providers, clinical managers, nurse navigators, and oncology administration
- A community engagement team including cancer survivors, caregivers, and community advocates, as well as members of the current UCCCC Community Advisory Board and the UCM Cancer Patient and Family Advisory Council

Successes

Clinical Trial Enrollment:

- Navigators worked with clinical trial coordinators to provide education regarding clinical trials and clinical trial availability and what to expect.
- Clinical trials coordinators then worked on narrowing the appropriate trials and set time to discuss the trial and enroll patients.
- Working in concert provided patients with a better understanding of clinical trials and increased their comfort level in enrolling.
- 181% increase in enrollment over a 6-month period.

Data Collection Improvements driving patient care impact:

- Collecting metrics consistently and over time has been a key factor in improving patient outcomes.
- Data collected post-award improved over pre-award data. Measures such as # of days to diagnosis, clinical trials enrollment, # of patients navigated have markedly improved.
- Proactive capture of barriers to care has allowed grantee to be more intentional in how to enhance UCM's supportive oncology services to best help patients through their cancer journey.





Enhancing Patient Navigation at UK Markey Cancer Center

Social determinants of health (SDOH) can pose barriers to individualized, timely, and equitable access to cancer care, especially for socially disadvantaged patients. SDOH are major factors driving cancer burden in Kentucky (KY); A third of KY's 120 counties are classified as having "persistent poverty." The University of KY Markey Cancer Center (MCC) is the only NCI- designated cancer center in KY.

A significant challenge experienced in MCC's PsychOncology navigation program is a high volume of patients with psychosocial distress and limited ability to address SDOH. Another challenge is the lack of tools for tracking and reporting metrics for continuous improvement in MCC oncology navigation. MCC seeks to build on existing components of MCC's PsychOncology navigation program using the novel Comprehensive Connected Cancer Care (C4) Navigation Model, a multi-level approach to leverage digital technology and combine remote psychosocial screening, patient and family navigation, and patient education.

Strategies

- The work aims to accomplish the following within MCC's PsychOncology navigation program:
 - Co-design a quality improvement process with stakeholders to integrate the C4 Navigation Model.
 - Evaluate implementation of the C4 Navigation Model using robust process and outcome metrics.
 - Plan for long-term sustainability of the C4 Navigation Model and its future scalability.

The overall goal is to enhance MCC's existing PsychOncology navigation program by augmenting innovative technology-based tools, increasing capacity to improve health equity through addressing SDOH, and utilizing continuous quality improvement methods.

Successes

Improved Data Accuracy

- The data across the four reporting points continues to increase in accuracy.
- Prior to the Navigation Capacity Building grant, the Psych-Oncology team documented activity both in spreadsheets, and also, within the EHR system.
- To address double documentation, EPIC flowsheets and Tableau reports were built by Psych-Oncology and UK IT/EPIC teams to eliminate duplicate data entry, increase accuracy, and facilitate reporting.
- The key element in documented improvements was starting with a clear definition for each metric (numerator and denominator), mapping these definitions to discrete data points in the EHR, and working with EPIC teams to clarify and refine the data pulled into either Tableau or custom reports. These initial steps were essential to being able to analyze any potential improvements.
- The "No Show Rate" for navigated patients appears to be much lower compared to the no show rate for non-navigated patients.

"The most impactful outcome of this funding is having a patient navigator within the Psych-Oncology office to work with social workers to expand the capacity to address patients' health-related social needs. Also, the increased capacity to capture, track, analyze, and report on navigation metrics has facilitated raising awareness and understanding of the critical need for navigation services."

-UK Markey Cancer Center Project Team



UNC LINEBERGER COMPREHENSIVE CANCER CENTER

Implementing Navigation Decision Support to Enhance Oncology Care Equity

For cancer patients, delays in beginning treatment and stopping treatment early disproportionately affect racial and ethnic minorities and those living in rural or under-resourced communities. At University of North Carolina (UNC) Health: ~48% of patients reside in rural communities, and 5% reside in one of ten persistent poverty counties in North Carolina; additionally, 25% of patients are people of color, including 20% who are Black or African American. UNC will test how best to incorporate navigation decision support tools designed specifically to help care teams reduce inequalities in timely start of treatment and more tolerable treatment.

Strategies

The project focuses on patients with hematologic or gastrointestinal cancer who are being treated at either of two large UNC Health facilities, the North Carolina Cancer Hospital (NCCH) or UNC REX Cancer Care. The tools used include an initial patient assessment:

- Social and clinical information.
- Tracker to follow time from diagnosis to beginning of treatment.
- Predictive model to assess a patient's risk.

The global aim of the project is to improve cancer patient outcomes and equity, throughout UNC Health facilities and more broadly.

Successes

Tool Development:

- **Navigation assessment score** is now 'hardwired' within the electronic health record (EHR) and used throughout the Oncology Central Navigation program.
- The time-to-treatment ticker has been similarly built within the EHR, optimized through small-scale tests of change, and spread to the oncology central & clinical navigation teams and/or nursing teams across six UNC Health facilities.
- **The clinical risk calculator**, although not yet integrated within the electronic health record, is currently operational in the context of a remote symptom monitoring pilot at UNC Health's academic medical center.

Sustainability:

• ACS funding helped us **successfully advocate within UNC Health for the development of the informatic infrastructure needed to support PIN billing**—a key need for program sustainability.

"ACS funding enabled the ability to measure our program's reach and impact. Among the data we are reporting bi-annually to the ACS, on the one hand, we were **most interested (and excited) to see the downward trend in time to treatment**. Increasing the proportion of people seen who go on to receive their cancer treatment at UNC (retention) and the timeliness of the care we deliver has been a service line focus over the past year. It is in part through this rapid access program that we have been able to hire two additional oncology patient navigators to the central navigation team." - UNC Project Team



USC Norris Comprehensive Cancer Center Keck Medicine of USC

Navigation Capacity Building Initiative Program at USC Norris

The USC Norris Comprehensive Cancer Center (NCCC) is one of the first NCI-designated cancer centers in the US that provides cancer treatment to patients in Los Angeles County (LAC), which includes multiple disparate populations. Patient navigation (PN) interventions that address social determinants of health (SDOH) have not been integrated into clinic-based programs at most NCI designated cancer centers due to limited capacity to screen patients for SDOH, lack of knowledge about SDOH among providers and PN staff, and the absence of clinical workflows to navigate patients to social services.

Additionally, limited efforts have been made to evaluate the impact of SDOH based navigation on clinical metrics that include completion of treatment, satisfaction with cancer care, and referral to clinical trials. The goal of the project is to enhance the capacity and sustainability for PN at the NCCC and throughout LAC.

Strategies

The project aims to improve the quality and sustainability of clinic-based patient navigation by:

- Using a data-driven strategy to screen cancer patients for SDOH.
- Providing education and training on SDOH to health care providers and navigators.
- Developing procedures to implement SDOH-based navigation into the clinical workflow.
- Evaluating the effects of SDOH-based navigation on completion of treatment, patient satisfaction with care, and referral to clinical trials.

Successes

Process Improvements:

- Identified a validated SDOH screening tool that could be implemented into navigation.
- Worked with the navigation team, operational leaders at USC Norris and Keck Medicine of USC, and clinical care staff to develop a preliminary workflow for screening cancer patients for SDOH as part of the Ralph Lauren Center for Cancer Prevention at USC Norris and are developing a SDOH navigation protocol.
- Developed a data driven tool to facilitate documentation of navigation delivery among nurse navigators. The
 team worked collaboratively with the navigator leaders at USC Norris to design an Oncology Nurse Navigator
 Note for integration into our electronic health record (EHR) system. The navigation note is designed to facilitate
 charting clinical navigation notes and generate reports on navigation metrics. The nurse navigator note is now
 being integrated into the EHR. The development of the note is a key element that contributed to a reduction
 in the number of days from diagnosis to initial treatment

"This project was instrumental in integrating patient navigation across the continuum of cancer care delivery. Specifically, we have a better understanding of the ecosystem for patient navigation at USC Norris across the continuum for cancer care delivery and have translated this knowledge into data driven tools, clinical workflows, and infrastructure to enhance the quality and impact of patient navigation. In addition to the navigation note described above, a Multidisciplinary Navigation Forum (MNF) is being established to provide infrastructure to standardize and integrate navigation at USC Norris."



ACS Cancer Treatment Support Navigation Programs



ACS CARES (Community Access to Resources, Education, and Support), is a program designed to provide non-clinical patient navigation support to those affected by cancer. The program has three components, which include a digital app, 24/7 access to our Cancer Helpline, where people can

be connected to ACS Programs and national/local resources and information, as well as personalized support from trained ACS volunteers through clinic sites and virtual support through the app. All levels of support utilize a social determinants of health assessment to identify unmet needs of patients and their caregivers. In 2025, ACS CARES will continue to evolve into a centrally integrated information and peer navigation hub to bolster patient engagement and empowerment. This includes the development of a proactive patient journey incorporating content across four domains – shared decision-making, health-related social needs, self-management, and social connection – through three distinct phases of treatment – diagnosis, active treatment, and post-treatment/survivorship.

2024 Program Highlights:

8,027 individuals assisted through the English and Spanish versions of the ACS CARES mobile app.

ACS CARES Clinic-Based Student Volunteer program expanded from **4 to 12 clinics**. Student volunteers spend an average of **78 minutes** per patient in direct assistance.

229 ACS CARES Virtual Community Volunteers were trained and supported **496** patients and caregivers.

ACS Leadership In Professional Oncology Navigation (LION)

Tapped by the White House as part of the Cancer Moonshot initiative, ACS launched a **standardized training and credentialing program in January 2024** for professional non-clinical patient navigators, to help health systems and other organizations deliver <u>essential support</u> to cancer patients and their families. ACS LION meets the Centers for Medicare & Medicaid Services (CMS) requirements for "Principal Illness Navigation" reimbursement and professional oncology navigation standards of practice (<u>PONT Standards</u>). ACS LION features:



In **January 2025**, ACS LION will offer a **new Clinical Trials Navigation Certificate**. The certificate will equip professionals providing navigation services with the knowledge and skills to make clinical trials more accessible to patients. The enhanced support from patient navigators will enable more patients to gain access to potentially lifesaving treatments and resources.



Thank you

for investing in the American Cancer Society and our mission to improve the lives of cancer patients and their families.

Because while cancer affects everyone, it doesn't affect everyone equally. Through our commitment to patient navigation, we are working to ensure everyone has a fair and just opportunity to prevent, detect, treat, and survive cancer.





Patient Navigation Sustainability Assessment Tool PNSAT



Staples ES and Dwyer AJ. (2023). Patient Navigation Sustainability Assessment Tool – Short Version. Colorado School of Public Health and University of Colorado Cancer Center, Aurora, CO.

The PNSAT sustainability assessment tool was created by the Colorado Cancer Screening Project, coordinated through the University of Colorado Cancer Center. It is a model to provide a framework that incorporates the interdependent components needed for a sustainable navigation program.

Collected Metrics Guide

Domain: Operations Management

Navigation Caseload: Number of new cancer patients navigated per month

No-Show Rate: Number of navigated patients who do not complete a scheduled appointment per month

Domain: Psychosocial Support, Assessment

Number of navigated patients per month who received psychosocial distress screening at a pivotal medical visit

Domain: Coordination of Care/ Care Transitions

Barriers to Care: Top three barriers to care identified by the program

Treatment Compliance: Percentage of navigated patients who adhere to institutional treatment pathways per quarter

Diagnosis to Initial Treatment: Average number of days from date of diagnosis to date of first treatment for navigated patients

Clinical Trials Education: Number of patients educated on clinical trials by the navigator per month

Clinical Trials Referral (optional): Number of navigated patients per month referred to clinical trials staff

Additional progress report requirements include:

Aggregate demographic data: age range, race/ethnicity, gender identity, sexual orientation, primary cancer type, insurance status, and residential zip code

Brief narrative update, impact/case study, and any materials created

Financial report

Core project metrics monitored by the learning community to assess the impact of grantees' improvement strategies