



ACS NNRT Patient Navigation Legislative Toolkit

This toolkit is comprised of several documents to help advocate for legislation that will increase access to patient navigation services.

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I. Issue Background & ACS NNRT Overview

Issue Background

Patient navigation is the individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality health and psychosocial care. Patient navigation has evolved tremendously in the past few decades. In 1989, the American Cancer Society (ACS) National Hearings on Cancer in the Poor highlighted the substantial barriers and discrimination many people with limited financial means face when confronted with cancer and identified patient navigation as one of the solutions to these barriers.

Soon after, patient navigation was developed in the 1990s by physician and oncologist Harold P. Freeman at Harlem Hospital in New York City. Dr. Freeman noticed that women in the nearby community were repeatedly coming to Harlem Hospital too late to be saved from breast cancer, even when they lived within walking distance of the hospital. As such, Dr. Freeman worked to identify people in the community who were interested in serving as patient navigators and his innovative program resulted in more Harlem women who developed breast cancer coming to the hospital for treatment before their cancer had reached a late stage. In this interview, Dr. Freeman shares more of that story.

- [Dr. Harold Freeman interview with Katie Couric about founding of Patient Navigation](#). Learn more about the history of patient navigation [here](#).

NNRT Overview

The American Cancer Society National Navigation Roundtable (ACS NNRT) was established in 2017. The ACS NNRT is a national coalition of 150+ member organizations to advance navigation efforts that eliminate barriers to quality care, reduce disparities, and foster ongoing health equity across the cancer continuum. The American Cancer Society provides organizational leadership and expert staff support to the ACS NNRT. ACS NNRT membership includes partners from diverse sectors including academia, public health, advocacy and survivor groups, professional societies, industry, training, and state and federal agencies.

On June 14, 2022, ACS NNRT membership published a collection of 13 articles about patient navigation in the journal *Cancer* aimed at exploring cancer care disparities across the cancer continuum by highlighting the critical role of evidence-based navigation in reducing barriers to care for individual patients and their loved ones. Learn more at [navigationalroundtable.org](https://www.navigationalroundtable.org).

- [ACS National Navigation Roundtable \(ACS NNRT\) Factsheet](#) (May 2023)
- [The National Navigation Roundtable's Patient Navigation Supplement](#) (June 2022)

Oncology patient navigators work in diverse settings, from community-based programs to comprehensive cancer centers, to improve outcomes in underserved populations by eliminating barriers to timely cancer prevention, early detection, diagnosis, treatment, and survivorship in a

culturally appropriate and competent manner. This article from the ACS NNRT Workforce Development Task Group clarifies the roles and responsibilities of entry, intermediate, and advanced level cancer patient navigators, detailing competencies that apply to patient navigators, nurse navigators, and social work navigators. Additionally, it serves as a resource for administrators to create job descriptions based on specific expertise levels and for patient navigators to advance their oncology careers and attain higher levels of expertise.

- [Patient Navigation Job Roles by Levels of Experience: Workforce Development Task Group, National Navigation Roundtable](#) (February 2024)

The Professional Oncology Navigation Task Force includes several leading oncology-focused professional organizations and patient advocacy groups. In 2022, the Professional Oncology Navigation Task group updated and standardized the terminology for various types of patient navigators, a move aimed at enhancing the integration of navigators within healthcare teams and improving care coordination. As such, the Professional Oncology Navigation Task Force developed the Oncology Navigation Standards for Professional Practice, a set of oncology patient navigation standards intended to provide guidance on the knowledge and skills that all professional navigators should possess. According to these Standards, roles categorized as professional navigators include oncology patient navigators and clinical navigators, specifically oncology nurse navigators and oncology social work navigators. This standardization of navigator roles and responsibilities is expected to lead to better collaboration and more efficient patient care.

These Standards also establish benchmarks for healthcare employers and provide information for policy and decision makers, healthcare professionals, and the public to understand the role of professional oncology navigators.

ACS and ACS CAN recognize these standards and believe there should be baseline disease-specific training and education for patient navigators and that certification and training should be high-quality, evidence-based, and timely. The ACS NNRT also endorsed and continues to promote the adoption of these Standards.

- [Oncology Navigation Standards of Professional Practice](#) (March 2022)

II. Partners

a. The American Cancer Society

The American Cancer Society (ACS) is an experienced leader in patient navigation, working alongside partners and stakeholders for over 30 years to establish the field of navigation. ACS believes that patient navigation is critical to improving access to care for everyone. Navigation can remove barriers and improve access to care through patient-centered support from screening through survivorship.

ACS has led and funded efforts to build navigation programs, supported public policy to support navigation, and studies the role and benefits of navigation.

ACS supports navigation through:

- [ACS CARES™ \(Community Access to Resources, Education, and Support\)](#), that connects people with cancer and caregivers to information and resources chosen for each person's needs through the ACS CARES™ app, ACS team members, or ACS volunteer support.
- [ACS Patient Navigation Roundtable](#), which shares research and best practices that support patient navigation, helps define navigator roles, and provides resources to help cancer navigation programs continue.
- [ACS Patient Navigation Initiative](#), giving grants, education, and support to 20 health systems that provide care to historically excluded populations.
- [ACS Global BEACON Initiative](#), that provides training, support, and grants for patient navigation programs in low- and middle – income countries.
- [ACS CAN's](#) policy priorities to support navigation with a multi-year campaign to get Medicare, Medicaid, and private insurance coverage and payment for patient navigators.
- [ACS Health Equity Ambassadors](#) work in their local communities to provide education for African American/Black, Asian, Hispanic/Latino, Native American and rural populations on cancer prevention and early detection.
- [ACS LION™ \(Leadership in Oncology Navigation\), Patient Navigation Training and Credentialing](#) to support the professional patient navigation workforce, and implementation support for providers and practices.
- [Learn more here.](#)

b. The American Cancer Society Cancer Action Network

ACS also works alongside the American Cancer Society Cancer Action Network (ACS CAN), ACS's nonprofit, nonpartisan advocacy affiliate that advocates for evidence-based public policies to reduce the cancer burden. ACS CAN has been a long-standing advocate in making patient navigation services available for everyone at risk of cancer, those diagnosed with cancer, and cancer survivors. Yet to date, patient navigation services are still absent or limited in many cancer programs and hospital settings due to cost concerns and lack of clinical reimbursement. ACS CAN is advocating for state and federal legislation and policies to increase access to patient navigation for people with cancer, prioritizing policies that create sustainable funding to ensure patient access to patient navigation services across the cancer continuum, which is further outlined in this toolkit.

c. Cancer Moonshot

The Cancer Moonshot was initially funded through the 21st Century Cures Act passed in 2016 as a White House initiative to mobilize a national effort to end cancer as we know it. In February 2022, the Biden Administration reignited the White House Cancer Moonshot initiative to reduce the cancer death rate by half over the next 25 years and improve the experience of people touched by cancer. Learn more about the White House Cancer Moonshot initiative at <https://www.whitehouse.gov/cancermoonshot/>.

As part of the Biden Administration's 2023 [Unity Agenda](#), President Biden set the goal of making navigation services accessible to Americans facing cancer. With leadership from the First Lady, as of January 1, 2024, the Biden Cancer Moonshot [delivered six codes](#) to report navigation services for payment. These first-time new reimbursement codes are for Principal Illness Navigation services, which allows providers to bill for patient navigation services for Medicare enrollees diagnosed with high-risk conditions, including cancer.

In addition to reimbursement codes, the Administration announced [new commitments](#) from seven leading health insurance companies, serving 150 million Americans, to cover navigation services, as well as commitments from 40 comprehensive cancer centers and community oncology practices to provide effective navigation services for serious health conditions, like cancer.

III. ACS CAN Advocacy Engagement

a. Regulatory Advocacy Engagement

The foundational work ACS CAN executed on patient navigation played a critical role in the Centers for Medicare and Medicaid Services (CMS) issuing first-time reimbursement codes for patient navigation services for those with serious illness, like cancer. The proposed codes were included in the final 2024 Medicare Physician Fee Schedule rule.

On July 13, 2023, the Centers for Medicare and Medicaid Services (CMS) released a proposed rule on the CY2024 Physician Fee Schedule (PFS). Included in the proposed rule was new reimbursement for certain patient navigation services. In response to the CMS Physician Fee Schedule proposed rule, ACS CAN issued two letters to CMS, one along with 59 partners, that provided comments on how the new navigation payment approach should be implemented. In November 2023, CMS issued the final rule on the new payment code, which reflected many of the recommendations made by ACS CAN and our partners.

- [ACS CAN Summary and Reaction CY2024 CMS Physician Fee Schedule Final Rule](#) (December 2023)

In response to the CMS Physician Fee Schedule proposed rule, ACS CAN issued two letters to CMS, one along with 59 partners, that provided comments on how the new navigation payment approach should be implemented. This is the coalition letter that was signed by organizational partners. ACS CAN filed

this coalition letter to elevate the patient navigation provisions of the proposed rule given that patient navigation is an enterprise priority.

- [ACS & ACS CAN and Partners Joint Comments on Patient Navigation Provisions of CY2024 Medicare Physician Fee Schedule Proposed Rule](#) (September 2023)

In response to the CMS Physician Fee Schedule proposed rule, ACS CAN issued two letters to CMS, one along with 59 partners, that provided comments on how the new navigation payment approach should be implemented. ACS CAN filed this second letter in order to comment on other provisions of the proposed rule that are also ACS CAN priorities.

- [ACS CAN comments on CY2024 Medicare Physician Fee Schedule](#) (September 2023)

On November 2, 2023, CMS released the final rule, and these adopted rules took effect on January 1, 2024. CMS refers to the new reimbursement codes for patient navigation as Principal Illness Navigation (PIN) services. This FAQ document answers questions about those PIN codes, as well as Principal Care Management Services Codes, which are similar codes providers can use.

- [Principal Illness Navigation and Principal Care Management Codes FAQ](#) (May 2024)

In response to the CMS CY2025 Physician Fee Schedule's Principal Illness Navigation provisions, ACS CAN once again drafted a sign-on letter with the ACS NNRT:

- [ACS, ACS CAN and Partners Joint Comments on Patient Navigation Provisions of CY2025 Medicare Physician Fee Schedule Proposed Rule](#) (September 2024)

b. State & Local Advocacy Engagement

Patient navigation is still absent or limited in many health care settings due to cost concerns and lack of reimbursement. However, some states currently allow Medicaid payment for services provided by Community Health Works (CHWs) through State Plan Amendments. The following documents list the states that currently allow Medicaid payment for services provided by CHWs through State Plan Amendment (SPAs), including one case study from Colorado.

- [State Policies for Expanding Medicaid Coverage of Community Health Worker \(CHW\) Services](#)
- [Summary of Medicaid State Plan Amendments for Community Health Workers](#)
- On May 10, 2023, Colorado approved [SB23-002 for Medicaid Reimbursement for Community Health Services](#), which ACS CAN supported. Learn more [here](#).

For more information on ACS CAN state legislative campaigns, please contact your state's ACS CAN government relations director or Cathy Peters at catherine.peters@cancer.org.

c. Federal Team Advocacy Engagement

In addition to policy pathways at the state level, ACS CAN continues to advocate for federal legislation and policies to increase access to patient navigation services for people being screened for cancer as well as individuals with cancer across the continuum of care, prioritizing policies that create sustainable funding.

- Federal Legislation ACS CAN Supports
 - [Patient Navigation Assistance Act \(HR 9285\)](#)
 - The Patient Navigation Assistance Act would require state Medicaid programs to cover patient navigation services for enrollees. Congressman DeSaulnier (CA-D) [re-introduced](#) the Patient Navigation Assistance Act on November 10, 2022, and [again](#) on September 3, 2024. ACS CAN endorsed this re-introduction and continues to advocate for the Patient Navigation Assistance Act. ACS CAN has supported this bill since the bill was first introduced in 2014 by former Congressman Steve Israel (D-NY).
 - [Community Health Worker Access Act \(S. 3892\)](#)
 - The CHW Access Act would improve reimbursement for CHWs, Promotoras, and Community Health Representatives (CHRs) in Medicare and Medicaid while expanding access to community-based services for enrollees in these major health programs. According to the bill language:
 - A CHW is a frontline health worker who is a trusted member of the community in which the worker serves or who has an unusually close understanding of the community served that enables the worker to build trusted relationships, serve as a liaison between health and social services and the community, facilitate access to services, and improve the quality and cultural competence of service delivery.
 - A promotora is a trusted frontline worker who primarily works in Spanish-speaking communities and who shares lived experiences, language, and culture with the populations served that enables the worker to improve individual, family and community health outcomes by serving as a liaison between health and social services and the community, facilitating access to services, and improving the quality and cultural competence of service delivery.
 - A CHR is frontline health worker who is a trusted member of a tribal community with a close understanding of the community, language, and traditions that enables the worker to serve as a liaison between health and social services and the community, facilitate access to services, and improve the quality and cultural competence of service delivery.
 - The bill would provide reimbursement and access without copays for two new categories of CHW services in Medicare: 1) services to prevent illness,

reduce physical or mental disability, and restore an individual to the best possible functional level; and 2) services to address social needs through education and referrals to health care and community-based organizations. Finally, the bill would support the work in several state Medicaid programs to expand access to CHW services by issuing guidance from the Centers for Medicare and Medicaid Services (CMS) and providing an enhanced Federal Medical Assistance Percentage (FMAP) for CHW services.

- In March 2024, Senator Bob Casey (D-PA) [introduced](#) the Community Health Worker Access Act. Sen. Casey's [1-pager with more info on the bill is here](#).

IV. ACS CAN Materials

a. Fact Sheets

- [Sustainably Funding Patient Navigation Factsheet](#) (April 2023) - This external factsheet was created to provide language to educate members of Congress.

b. Survivor Views

ACS CAN gives voice to cancer patients and survivors on critical public policy issues that affect their lives. As part of this effort, ACS CAN deploys surveys to better understand cancer patient and survivor experiences and perspectives, through our Survivor Views research panel. The panel is a group of cancer patients and survivors who respond to regular surveys and provide important insights to support ACS CAN's advocacy work at all levels of government. These are two surveys that included questions regarding patient navigation and the data can be used to underscore the need for access to these critical services.

- Fielded April 2-20, 2023, this survey explored 1,311 cancer patients' and survivors' experiences related to the need for patient navigators. The ACS CAN survey found an overwhelming majority of patients and survivors (91%) agreed that having access to a patient navigator is important for cancer patients, and 75% said it is very important. However, only 55% of those surveyed said their oncology provider had a patient navigator on staff – further emphasizing the need for sustainable funding models for patient navigation services. [Survivor Views: Majority Less Likely to Get Recommended Screenings if Coverage is Lost](#) (May 2023)
- Fielded May 16-26, 2022, this survey explored 1,241 cancer patients' and survivors' experiences and perspectives on patient navigation. Nearly all survey respondents (98%) agreed that having a single contact for the issues addressed by patient navigators is important for cancer patients, and 79% said it is very important. [Survivor Views: Copay Assistance and Patient Navigation](#) (July 2022)

c. Talking Points

Please see below for some talking points about patient navigation's return on investment as informed by findings from the [Community Preventive Services Task Force's \(CPSTF\)](#) which found that estimated values for colonoscopy reimbursement exceed the cost of the intervention, as well as increase breast and [cervical cancer screenings](#). Those talking points are below:

- Patient navigation services have shown to effectively increase cancer screening rates (for breast, cervical, and colorectal) among historically disadvantaged populations and lower income individuals. These services demonstrated that addressing barriers these communities commonly face leads to higher participation in screening programs.
- Patient navigation services for increasing cancer screenings are cost-effective and the return on investment is favorable as the reimbursement often exceeds the cost of the intervention.

Patient navigation services provide comprehensive support to patients, addressing barriers to screening. Providing cultural and language appropriate assistance is crucial to ensure that patients understand the importance of screening and feel comfortable accessing care.

d. Story Collection

While it can feel like you're looking for something very specific when you start looking for patient navigation stories, there are several different angles you could take when working with spokespeople and media. Here are a few potential storytellers:

- A health care provider, cancer center director who has seen patient navigation in action and what a difference it makes for patients or the reverse: the care provider who can speak to how hard it is for a patient to navigate the oncology maze and what a difference patient navigation can make for patients.
- A patient navigator who has assisted patients, caregivers and family to better understand the best treatment options, mental health support, assisted with clinical trials and the services they provide.
- Someone who had/was a caregiver for someone who had access to patient navigation during their cancer journey success or need for support.
- Someone at risk of cancer/a cancer patient/ a cancer survivor who benefited from having a patient navigator assigned to them during their care (we mention someone "at risk of cancer" to also capture someone who received preventive screening services through navigation.)
- Someone who did not have/was a caregiver for someone who did not have access to patient navigation during their cancer journey and can speak to what a difference it could have made.