Nurse Navigator Resource Guide

for Non–Small Cell Lung Cancer

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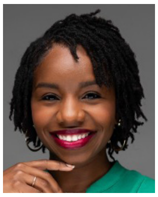
Acknowledgment

AstraZeneca would like to acknowledge the efforts and dedication of the Non-Small Cell Lung Cancer Steering Committee members who dedicated their knowledge, time, and efforts to enhance the care of patients with cancer through the development of the Non-Small Cell Lung Cancer Resource Guide for Navigators.

Cheryl Bellomo, MSN, RN, HON-ONN-CG, OCN
Oncology Nurse Navigator
Intermountain Cancer Center Cedar City Hospital
Cedar City, UT

Kristi Cobb, ONN-CG, RN
Lung Nurse Navigator
Baptist Healthcare
Pensacola, FL



Zilipah Cruz, MSN-RN, ONN-CG
Senior Director
Intake | Navigation | Survivorship | Community Outreach
Oncology Service Line
Orlando Health Cancer Institute
Orlando, FL

Kammi Fox-Kay, MSN, RN, AOCNS, ONN-CG(T)
Thoracic Oncology Nurse Navigator
Franciscan Health Crown Point Indiana
Crown Point, IN

Amy Jo Pixley, MSN, RN, FACCC, OCN, ONN-CG(T)
Thoracic Oncology Nurse Navigator
Penn Medicine Lancaster General Health
Ann B Barshinger Cancer Institute
Lancaster, PA

Academy of Oncology Nurse & Patient Navigators: Mission and Vision

The mission of the Academy of Oncology Nurse & Patient Navigators (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. Cancer survivorship begins at the time of cancer diagnosis. One-on-one patient navigation should occur simultaneously with diagnosis and be proactive in minimizing the impact treatment can have on quality of life. In addition, navigation should encompass community outreach to raise awareness targeted toward prevention and early diagnosis, and must encompass short-term survivorship care, including transitioning survivors efficiently and effectively under the care of their community providers.

The vision of AONN+ is to increase the role of and access to skilled and experienced oncology nurse and patient navigators so that all patients with cancer may benefit from their guidance, insight, and personal advocacy.

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Introduction

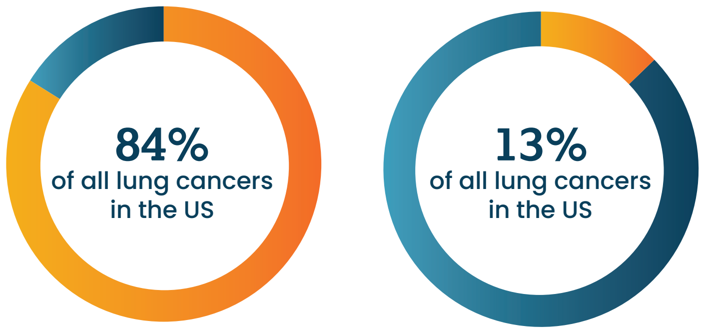
Lung cancer treatment has evolved to become increasingly specialized with the discovery of new therapeutic approaches and genomic subtypes. With these advancements, a higher level of care coordination within the healthcare delivery framework is now necessary to deliver optimal outcomes. Within this framework, the role of the navigator has become essential in delivering patient-centered care. By identifying and addressing barriers to diagnosis and treatment, providing patient and caregiver education, offering psychosocial support to those undergoing treatment, coordinating care, advocating for patients, and promoting both survivorship and end-of-life care, navigators can help to ensure the effective delivery of comprehensive, multidisciplinary care.

In lung cancer care, the services offered by navigators vary widely. Navigators maintain an ongoing relationship with patients, supporting them from diagnosis through treatment and follow-up. In larger programs, navigators may be assigned to specific phases of the care process, ensuring seamless coordination as patients transition across the care continuum. Depending on the structure of the program, some navigators might meet several newly diagnosed lung cancer patients in a single day, while others may encounter only 1 new patient over the course of weeks or months. To address this variability, the toolkit provided here consolidates key resources and offers practical advice to help navigators effectively assist patients and their families or caregivers, especially those coping with advanced non–small cell lung cancer (NSCLC).

Epidemiology

Lung cancer represents a significant majority of cancer cases and deaths in the United States; in 2025, there are estimated to be 226,650 cases and 124,730 deaths.[1] Lung cancer can be subdivided into 2 primary histological categories; NSCLC and small-cell lung cancer (SCLC). NSCLC is more common, representing approximately 84% of all lung cancers (**Figure 1**).[2] Between 2010 to 2017, 1.28 million new NSCLC cases were reported in the United States.[2] The 1-year survival for patients with NSCLC was 55.1%, but 5-year survival dropped to 26.4%.[2]

Figure 1: NSCLC and SCLC Epidemiology in the United States



Non-Small Cell Lung Cancer (NSCLC)

Small Cell Lung Cancer (SCLC)

NSCLC, non–small cell lung cancer; SCLC, small-cell lung cancer.

The pathophysiology of both NSCLC and SCLC are similar, yet both are complex and not completely understood. It is theorized repeated exposures to carcinogens lead to dysplasia of the lung epithelium.[3] If exposures are consistent for long enough, they may lead to genetic variants affecting protein synthesis.[3] This will ultimately disrupt the cell cycle, promoting carcinogenesis.[3]

Etiology

Etiology of NSCLC is more widely understood. Possible causes of lung cancer may be environmental or genetic. Some risk factors may be modifiable, while others are not. By far, the most well-known risk factor for NSCLC is smoking, which accounts for 90% of all lung cancer cases.[3] Nurse navigators play a critical role in the collection of smoking history, and in some cases, providing smoking cessation options for patients diagnosed with NSCLC. Smoking cessation shortly after NSCLC diagnosis has been demonstrated to have a positive association with mortality.[4] Vaping has increased in popularity in recent years, and the combination of vaping and smoking increases the risk of lung cancer by 4-fold.[5] In addition, exposures to other materials such as asbestos, certain metals, and radon may increase the risk of carcinogenesis.[6] Certain diseases such as pulmonary fibrosis and HIV have been shown to have an increased risk of lung cancer diagnosis.[6]

Signs and Symptoms of NSCLC

Signs and symptoms may be nonspecific. Patients may present with intrathoracic symptoms including coughing, hemoptysis, chest pain, dyspnea, and hoarseness.[6] Symptoms separate from the respiratory system may also be present, including loss of appetite, unexpected weight loss, fatigue, and swelling in the face or veins of the neck.[7] These symptoms in combination with additional risk factors may lead a healthcare provider to believe a patient may be at risk for NSCLC, and thus in need of more advanced screening and diagnostic methods. Nurse navigators may have multiple roles to play in this process, depending on their institution. Often, patients will want to understand what signs and symptoms can be expected from their disease, even prior to biopsy and initial screenings. Duties may include informing the patient of what signs and symptoms they can expect, preparing the patient for screening, providing education, and following up on the results of the identified lung nodules.

Diagnostics and Biomarker Evaluation

Diagnostics and screening of lung cancer can be done in a multitude of ways; in fact, multiple methods may be regularly used. Per US Preventative Service Task Force recommendations, patients between the ages of 50 to 80 years who have a 20 pack-year or more smoking history and either smoke now or have quit within the last 15 years are eligible for preventative screening.[8] The only recommended preventative screening test for lung cancer is a low-dose computed tomography (CT) scan. Physical and imaging studies such as a CT scan of the thorax, positron emission tomography scan, or magnetic resonance imaging may be utilized to visualize and confirm the presence of a tumor. In the case of low-dose CT scans, a Lung-RADS score may be utilized to evaluate the readings and determine possible next steps. If a tumor is present, a tissue or liquid biopsy may be utilized. The method of obtaining the biopsy may differ by institution, patient tolerability, and the size of the tumor. Per NCCN, tools which should routinely be available to perform a biopsy include thoracentesis, mediastinoscopy, image-guided biopsy, endobronchial ultrasound-guided biopsy, bronchoscopy, or fine needle aspiration.[9] Some centers with appropriate capabilities may rely on robotic endoscopy to diagnose lung cancers.

Table 1: Common Gene Alterations in NSCLC

Gene Variants	Gene Fusions	Biomarkers for Immunotherapy
BRAF	*ALK*	PD-L1
EGFR	*MET*	
HER2	*NTRK*	
KRAS	*RET*	
	ROS1	

NSCLC, non-small cell lung cancer; PD-L1, programmed death-ligand 1.

Evaluations of biopsy results are first done histologically through gross and microscopic examination.[10] In tandem, biopsy results may be evaluated for the presence of gene alterations such as variants, fusions, or certain biomarkers. Gene alterations are evaluated through next-generation sequencing (NGS). NGS offers a more precise diagnosis and classification of the disease, a more accurate prognosis, and in most cases, the identification of gene alteration provides treatment-directed guidance.[11] Liquid samples may be evaluated by NGS, though NGS would primarily be performed on circulating tumor DNA (ctDNA).[12] Common actionable genetic variants with therapeutic options can be seen in **Table 1**. Results will be utilized in conjunction with previous imaging and diagnostic tests to determine actionable variants as well as initial and subsequent optimal treatment options for the patient.

Staging of NSCLC

Staging of the progression of disease will be determined by imaging studies. TNM staging describes NSCLC on three major factors; the primary size of the tumor (T), the spread of the cancer to nearby lymph nodes (N), and whether the cancer has metastasized (M).[13] The TNM system may also be simplified into stages 0 to IV. Across both of these staging systems, a higher stage will indicate a more severe or metastatic disease.

UNMET NEEDS

Screening Requirements and Molecular Screening

An unmet need does exist for patients diagnosed with NSCLC. Firstly, screening requirements for NSCLC are not clear. It is recommended that patients aged 50 to 80 years and who incurred at least 20 pack-years of cigarette smoking undergo yearly CT scans. However, for patients that do not fall into the above criteria, there is lack of clarity on whether these patients should be screened for lung cancer or not.[14] As the current screening criteria primarily capture heavy smokers, NSCLC cases have been on the rise in patients with a smoking history of 20 to 29 pack-years.[15]

Though smoking is one of the primary risk factors for lung cancer, those that have never smoked are still at some risk of lung cancer. In the United States, approximately 10 to 20% of lung cancers (20,000-40,000 cases) occur in patients who have never smoked or who smoked less than 100 cigarettes in a lifetime.[16] Even being exposed to secondhand smoke from friends and family members, air pollution, or radon can increase the risk of lung cancer in patients who have never smoked.[16] Of the number of patients who have never smoked, secondhand smoke may contribute to approximately 7000 lung cancer deaths each year.[17]

There are also unmet needs within molecular screening methods. Tissue and liquid biopsy are utilized in determination of actionable biomarkers, and each has its own favorable attributes. While liquid biopsy can assess ctDNA from all tumor sites, remain relatively noninvasive, and can be repeated serially, tissue biopsy can be assessed for tumor mutational burden, which can be measured as a predictor for the efficacy of immune checkpoint inhibitors.[18] Therapeutic treatment options, while having evolved rapidly in recent years to include a multitude of mechanisms of actions, are primarily utilized in the first-line metastatic setting. When primary or acquired resistance occurs, little evidence exists for effective treatment options in the second line and beyond setting.

> Patients often report emotional distress regarding lung cancer survivorship, which requires consistent patient education and shared-decision making in conjunction with emotional, social, and financial support.

Physical and Emotional Burden

Furthermore, as therapies evolve, poly-pharmacy regimens are becoming the norm. While essential to extend the life and combat the disease of the patient, there is a detrimental effect as to the adverse-event (AE) profile that patients will experience. Not only will the number of AEs increase, but by compounding agents with similar AE profiles, the severity of AEs that the patient is already experiencing with a single agent may increase. More than 95% of patients report at least 1 AE from their regimen, with anxiety, fatigue, and shortness of breath being the most common long-term AEs.[19] Emotional burden is prevalent among patients with NSCLC. Patients often report emotional

Figure 2: Lung Cancer Disparities Among Black Individuals

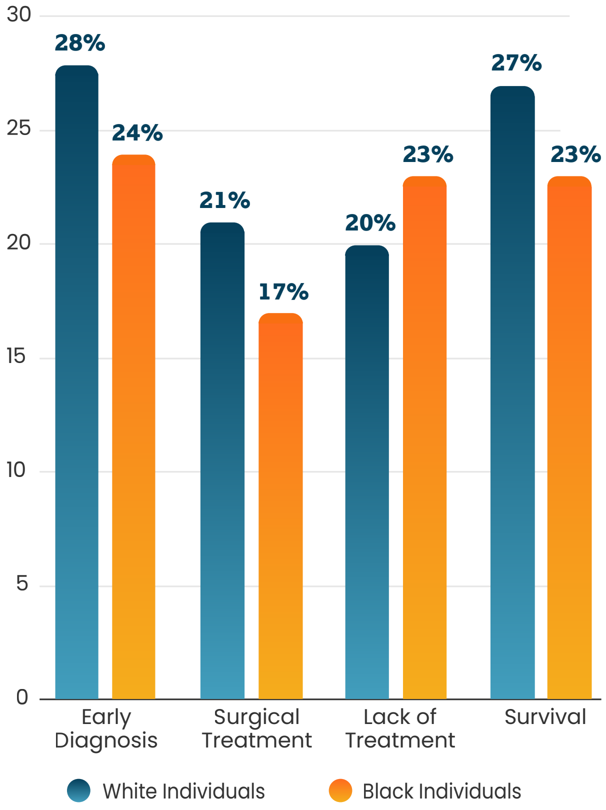
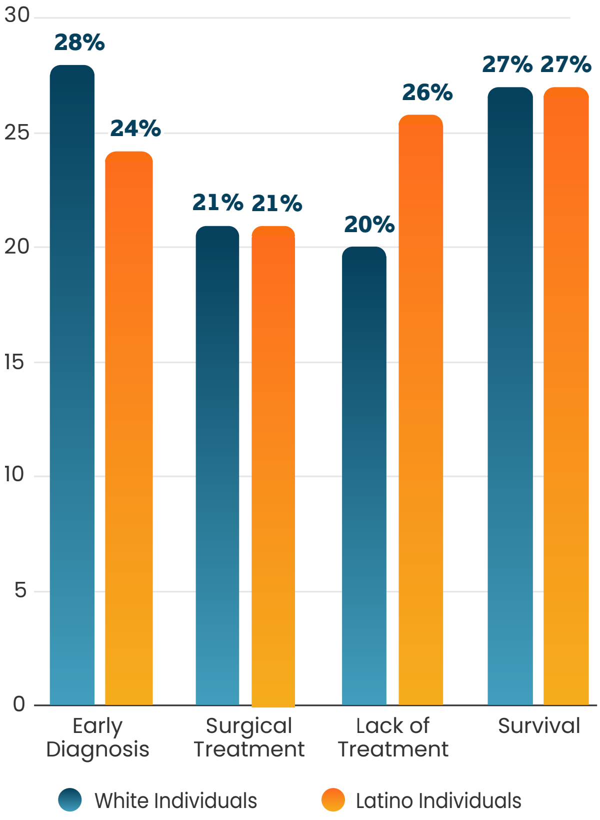


Figure 3: Lung Cancer Disparities Among Latino Individuals



> Comprehending the foundations of NSCLC, from staging and grading to the details revealed by laboratory testing, imaging, and genetics/genomics, allows navigators to synthesize the information and skillfully provide optimal care to patients and their families.

distress regarding lung cancer survivorship, which requires consistent patient education and shared-decision making in conjunction with emotional, social, and financial support.[20]

Racial and Age-Related Disparities

Racial and age-related disparities for patients with NSCLC exist. Compared with White individuals, Black individuals with lung cancer were 15% less likely to be diagnosed early, 12% more likely to not receive any treatment, and 16% less likely to survive 5 years (**Figure 2**).[21] Latino individuals show similar findings; they are 17% less likely to be diagnosed early and 30% more likely to not receive any treatment.[21] However, Latino individuals with lung cancer showed similar survivorship compared with White individuals (**Figure 3**).[21] Older patients are less likely to receive treatment for NSCLC. A study examining the receipt of treatment among different age and comorbidity groups found that for patients with localized NSCLC, surgery interventions were more common in those aged 65 to 74 years with severe comorbidities compared with those aged 75 to 84 years with no comorbidity (57% vs 50%; *P*<.001).[22]

Aside from treatment and survivorship, there are significant disparities in the screening of lung cancer as well. A study within the Durham Veterans Affairs Health Care System demonstrated that compared with White veterans, Black veterans were 34% less likely to complete lung cancer screening after referral.[23] In addition, compared with those who have commercial insurance, veterans with Medicaid insurance were less likely to undergo biomarker testing.[24] Higher mortality risk was also seen in patients with Medicaid insurance compared with commercially insured patients (hazard ratio, 1.23; *P*<.001). Centers where patients receive care for their NSCLC may also play a role in outcomes. A study demonstrated that in 2013, patients being treated at academic centers showed greater survival outcomes compared with patients being treated in community centers (23.7% vs 16.2%).[25]

Navigators working with patients with NSCLC should have a basic understanding of staging, diagnostic, and treatment options to provide optimal care. Comprehending the foundations of NSCLC, from staging and grading to the details revealed by laboratory testing, imaging, and genetics/genomics, allows navigators to synthesize the information and skillfully provide optimal care to patients and their families.

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Non–Small Cell Lung Cancer Myths and Facts

Though non–small cell lung cancer (NSCLC) is one of the most common forms of cancer, knowledge regarding the disease remains relatively low among the general population. The combination of varying levels of health literacy and complex medical knowledge make it challenging to distinguish between the facts and myths surrounding NSCLC as both a disease and its treatment. This lack of knowledge leads to various misconceptions about NSCLC, which are detailed in **Table 1**.[1-4]

Table 1: Myths and Facts of NSCLC

Myth	Fact
Treatments are too expensive, and often will not be covered	While financial aspects of treatment are a major concern, financial navigation services may be the key to identifying strategies which minimize the patient's out-of-pocket costs
Experiences with lung cancer will be the same for all patients	There are various patient characteristics such as age, race, sex, and comorbid conditions that may differentiate one patient's experience with lung cancer from another Nurse navigators should educate patients on how goals of care and treatment itself are highly individualized with no one journey being the same
NSCLC only affects smokers	While smoking is a large risk factor for NSCLC, individuals who have never smoked are also at risk A study of 285 NSCLC patients showed that 56 of them had never smoked[1]
NSCLC is self-inflicted	Due to stigmas of smoking and its relation to NSCLC, patients can often feel guilt or shame.[2] These lead to social isolation, reluctance to share a diagnosis, and stress with family and friends. The belief that NSCLC is a punishment for their actions can even lead to reluctance to start treatment or loss of hope Navigators play a key role in assessing distress, providing solutions to psychosocial issues, and help with addressing these feelings. The words HCPs and nurse navigators utilize matters; a recent study of World Conference on Lung Cancer presentations demonstrated that after the release of the International Association for the Study of Lung Cancer Language guide, almost half of the presentations utilized person-first, non-stigmatizing language.[3] Choosing words carefully and decreasing the stigma around smoking may increase the patient's motivation to become more involved in their treatment
Once a patient is diagnosed with NSCLC, they do not have much longer to live	Patients diagnosed with NSCLC may go on to lead very long lives A study of patients with stage IV NSCLC who had survived greater than 3 months showed 1-, 2-, 5-, and 10-year survival rates of 74%, 49%, 16%, and 5%, respectively[4]

Table 1: Myths and Facts of NSCLC (continued)

Myth	Fact
Patients with NSCLC are less active socially and have a worse quality of life	Patients with NSCLC should stay active socially through several means including joining support groups and seeking help from mental health professionals While treatment of NSCLC can have diminishing effects on quality of life, nurse navigators play a large role in mitigating those effects. Managing adverse events and building trust with the patient to better assist them with their individual needs are just some of the ways nurse navigators can assist. Palliative care team members can also play a crucial role in reducing pain and challenges a patient may be facing
The goals of treatment are always to cure NSCLC	Goals of treatment for a patient with NSCLC are individualized based on their stage of disease and what they value. While curative intent may be a goal some of the time, often goals can be either to prevent progression or to provide comfort to patients with advanced disease As navigators interact with patients, instilling an understanding of their disease and making realistic goals of care are crucial to a successful treatment plan. Goals of treatment should also be adjusted based on evolving patient needs
If a patient has a gene variant associated with NSCLC, their children are at risk of inheriting those variants	Variants associated with cancer can be inherited in the case of germline mutations. However, most gene variants are classified as acquired, which are not inherited.[5]

HCP, healthcare provider; NSCLC, non–small cell lung cancer.

Patients with NSCLC, along with their friends, family members, and even some healthcare providers and navigators, may hold misconceptions about the disease. Understanding the facts, dispelling myths, and sharing accurate information are essential aspects of effective communication and education for navigators.

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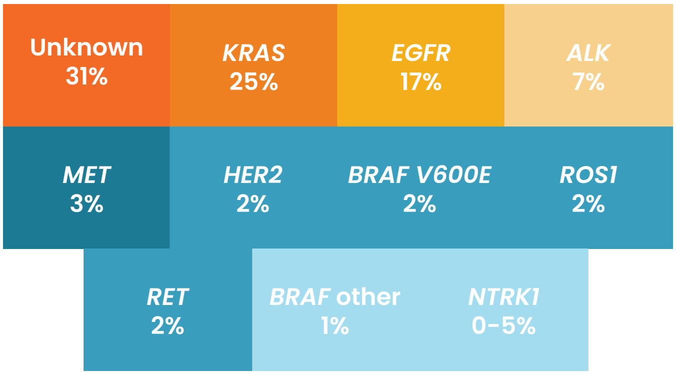
The Navigator's Role in Biomarker Testing

Figure 1: Driver Mutations in Lung Adenocarcinoma[2]



A key portion of non–small cell lung cancer (NSCLC) treatment is molecular testing, which is the identification of variants in tumor tissue.[1] Lung cancers can have a variety of alterations, and these can differ based on location and histology. **Figure 1** shows the common driver mutations that are found in lung adenocarcinoma.[2] These variants will ultimately become the basis of treatment options for the patients. Currently, time from pathologic diagnosis to treatment benchmarks is approximately 30 days. However, obtaining molecular testing results may account for half of the time.[1] This can be attributed to several factors including provider ordering, delays with the testing provider, or lack of follow-up. As testing is directly related to treatment, reduction in the delays of testing can lead to more prompt treatment, improved outcomes, and decreased costs.[3]

The role of the nurse navigator in biomarker testing may differ depending on the institution's nurse navigation framework. In the initial stages of diagnosis, the nurse navigator may be responsible for preparing the testing order once the provider decides which test is appropriate.[3] Nurse navigators may also be responsible for coordinating the biopsy for the patient.[3] Once the biopsy is completed, the nurse navigator will watch for the final pathology report and order additional molecular testing if needed.[3] If additional testing is needed, the nurse navigator will follow up on biomarker testing results in the reference portal, and forward them to the treating provider, who will use the results to guide treatment decision-making.[3] This process can be seen in **Figure 2**.[3] Throughout this entire process, the nurse navigator will have to regularly communicate and relay information from healthcare team members including the radiologist, pathologist, and perhaps the pulmonologist or oncologist.

> Explaining the need for testing, what testing will consist of, and how it will factor into the patient's individual treatment plan are core duties of the nurse navigator.

Nurse navigators may be responsible for patient education during the initial testing. Explaining the need for testing, what testing will consist of, and how it will factor into the patient's individual treatment plan are core duties of the nurse navigator. Education may additionally consist of setting expectations for the patients based on genetic results. Some gene variants may have many treatment options, while others have minimal options. Helping the patient understand what their specific gene variant means and aligning the goals of care to realistic expectations can be a core value of the nurse navigator. In some cases, access and ensuring minimal financial burden to the patient may be part of the nurse navigator's daily duties. In 2018, Centers for Medicare & Medicaid Services (CMS) determined next-generation sequencing was a reasonable and necessary diagnostic laboratory test.[1] Tests are often covered when performed by a Clinical Laboratory Improvement Amendments-certified laboratory and ordered by the treating physician.[1] Although the utility of these tests is recognized by clinical guidelines, payer coverage tends to vary. Furthermore, the

Figure 2: Role of the Oncology Nurse Navigator (ONN) in Biomarker Testing and Screening[3]

Before Diagnosis

- The treating provider estimates the stage of disease based on available imaging
- Depending on the institution, the nurse navigator (NN) or provider may facilitate the biomarker testing order
- The treating provider outlines the approach to collecting the biopsy (tissue, liquid, mode of collection, etc.)
- The NN organizes and coordinates the biopsy process with the appropriate healthcare team members and patient

Diagnosis

- The NN and treating provider monitor for the final pathology report
- Upon reviewing the final pathology report, the treating provider places the order for biomarker testing of the biopsy sample
- The pathologist processes and sends the sample to the reference lab for testing

Postdiagnosis

- The NN tracks the biomarker testing results through the reference lab portal
- When the biomarker testing report is available and finalized, the NN retrieves them and shares them with the treating provider
- The treating provider leverages the biomarker testing results to inform treatment decisions for the patient

Laboratory Date of Service Policy, or more commonly known as the 14-day rule, set out by CMS provides guidance on either billing the reference laboratory or hospital based on the day of patient discharge, which may further complicate the financial portion of biomarker testing.[1] It is important for the healthcare team to understand various laboratory billing and financial assistance programs as well as have a process in place with the individuals at your organization to ensure the cost does not fall onto the patient.[1] Most reference laboratories have financial assistance teams ready to work with healthcare providers to ensure tests are either covered, or there is a plan in place in case an insurance denial is received.[1]

While biomarker testing is necessary and reasonable, there are still significant challenges that occur with the process. Aside from insurance coverage issues already discussed, the availability and reliability of tests are an issue. Not all tests are readily available to every healthcare center. Furthermore, ordering procedures, portals, and obtaining test results may differ based on the company executing the test, increasing the burden on the nurse navigator. Obtaining adequate tissue material may be a barrier. Tissue samples may be limited; thus, obtaining a sufficient quantity of tissue to conduct molecular testing may be difficult. In these scenarios, liquid biopsy may be the more appropriate testing option.[1] Finally, provider preferences may play a role in what tests they order. Agreements with certain laboratories, speed or results, or a myriad of other reasons may push a provider towards one testing provider or another. However, it is important the provider becomes comfortable with multiple testing providers, including ordering and test interpretation. Some providers may want to start treatment as early as possible for the patient, even before biomarker testing results return. As biomarker testing provides a guide for and can optimize patient treatment options, it is important to understand how long biomarker testing may take, and construct a plan that may involve starting treatment immediately or waiting to incorporate the results of the biomarker testing.

As targeted therapies come to the forefront of the therapeutic landscape, the use of biomarker testing is a standard part of providing care to patients with NSCLC. Complete and comprehensive biomarker testing involving both tissue and liquid biopsy is a vital step in determining the optimal treatment plan for a patient with NSCLC. Utilizing both tissue and liquid biopsy testing modalities increases the likelihood of identifying actionable gene variants, while decreasing delays if staff are unable to collect enough sample through either liquid or tissue biopsy.

Lung navigators may be responsible for keeping track of the status of current tests and testing needs, as well as educating the patient; a deep understanding of the process of testing as well as the barriers along the way is crucial to providing optimized care. An understanding of these general processes and barriers can help the nurse navigator better understand the strengths and weaknesses of their institution's biomarker testing processes. From there, systematic improvements may be introduced to make testing more readily available to patients, allow for testing to be more rapid, and be less burdensome on the care team, leading to increased positive outcomes for patients with NSCLC.

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Barriers to Care Along the Pathway

One of the fundamental barriers of cancer navigation is overcoming obstacles which delay timely care. These challenges may arise from multiple sources, including patients and their caregivers, members of the healthcare team, or even broader systemic issues within the healthcare infrastructure. The following are examples of barriers that can be categorized based on whether the intervention is directed toward the patient and their family or primarily aimed at addressing issues within the healthcare team or system (**Table 1**).

Table 1: Common Barriers to Care

Patient Barriers to Care
Patient motivation
Literacy barriers
Distress
Financial and coverage issues
Transportation, housing and social barriers
Provider Barriers
Care teams and variability across processes
Inefficiencies of care
Accessing clinical trials
Healthcare System Barriers
Lack of resources
Lack of reimbursement
Access to outpatient diagnostics

PATIENTS

Patient Motivation

Patients and their families or caregivers facing NSCLC often encounter numerous psychosocial stressors within a compressed timeframe, particularly following a new diagnosis or during intensive treatments. Stressors may not need to come from just the clinical aspects of treating NSCLC; logistical concerns such as finance or ability to make appointments may also weigh heavily on the patient. These stressors can contribute to a decline in patient motivation as emotional and mental health challenges emerge, including varying levels of depression, anxiety, and even post-traumatic stress. Patients and their loved ones may experience overwhelming emotions, such as guilt, fear, anger, sadness, confusion, and a perceived loss of control, all of which can affect their readiness to engage in treatment and decision-making.

Literacy Barriers

Navigators must recognize that literacy extends beyond the ability to read and write. It also encompasses a person's understanding of medical concepts and their competence in managing health-related tasks. For many patients, the terminology utilized when discussing NSCLC can sound foreign, regardless of intelligence or education level. Barriers to health literacy may stem from obvious factors, like language differences, or more nuanced issues, such as stress, limited education, or an overwhelming clinical setting.

To address these barriers, navigators should begin by assessing the patient's preferred learning style and readiness to receive information. Considerations may include:

- Determining what the patient wants and needs to know
- Understanding the patient's preferred learning and communication style. Patients may prefer to learn through written, verbal, or visual means, and may prefer to communicate through portal messaging, email, or phone calls
- Determining the best language to deliver information to the patient
- Assessing what the patient already understands
- Identifying the patient's willingness and ability to learn
- Exploring the patient's priorities and uncovering any barriers to effective learning
- Ensuring understanding nonclinical aspects of care, such as how to utilize the patient portal

Navigators should also evaluate the most appropriate method, timing, and setting for delivering information. Questions to guide this process include:

- What essential information must the patient learn to avoid life-threatening risks?
- How and when can this information be most effectively delivered to the patient and their family?
- Why is this knowledge critical, and how can it best support the patient's care journey?

This learning needs assessment should be ongoing and included in each patient encounter, with findings shared among caregivers and healthcare providers to ensure consistent, patient-centered education.

> Navigators play a vital role in addressing distress by offering strategies for stress management, including relaxation techniques, mindfulness, and healthy coping mechanisms.

Distress and Its Causes

A lung cancer diagnosis can trigger profound social and emotional stress. Common causes of distress include uncertainty about prognosis, fear of treatment-related side effects, financial strain, and feelings of isolation. Patients and caregivers may struggle to cope with these challenges, leaving them vulnerable to emotional exhaustion. Navigators play a vital role in addressing distress by offering strategies for stress management, including relaxation techniques, mindfulness, and healthy coping mechanisms. To assess and monitor distress, the NCCN Distress Thermometer is commonly used in cancer care, both at initial evaluation and during follow-up assessments, ideally at every medical visit.[1] Other instruments utilized may be the Condensed Memorial Symptom Assessment Scale.[2]

Patients and caregivers coping with NSCLC face a heightened risk of distress due to the nature of the disease itself. Distress levels can fluctuate at various points in the care process, such as after learning the stage and grade of the cancer during diagnostic testing, making treatment decisions, awaiting the start of therapy, or gaining knowledge about side effect profiles of treatment. Regular distress evaluations are essential throughout the course of treatment to address the growing symptom burden, potential complications, and the complexity of managing multiple and sometimes simultaneous treatment modalities. Additionally, since patients may have fewer in-person visits to the care center, distress monitoring should continue during treatment breaks and into post-therapy surveillance utilizing tools like the Distress Thermometer through telephone or digital communication.[1]

Other factors unrelated to the cancer itself can further amplify distress. For instance, men may be less inclined to seek help when faced with cancer. Conversely, women are often more interdependent and may turn to family, caregivers, or peer support groups. Navigators play a key role in administering distress screening tools to both patients and caregivers, providing an opportunity to address concerns promptly throughout the care continuum. Even if distress levels appear minimal and do not warrant a referral, using the Distress Thermometer or other tools helps foster open communication, encouraging patients and caregivers to express how they are coping and to raise any issues the navigator or cancer care team can address.[1]

In cases where distress significantly impairs the patient's quality of life, navigators should consider referring patients to oncology social workers or mental health professionals who specialize in cancer care. These professionals can provide in-depth emotional support, helping patients and families process difficult emotions and navigate the psychological toll of the disease.

Navigator Interventions for Common Distress Symptoms

Mild distress symptoms, indicated by a Distress Thermometer ≤4, can typically be managed by the primary oncology care team, which often includes the navigator.[1] However, higher scores (≥4) may necessitate referrals for specialized support.[1] Common symptoms of distress include:

- Fear and anxiety about the future
- Anger and feelings of losing control
- Irregular sleep patterns
- Loss of appetite
- Concerns about social roles (eg, as a parent or partner)
- Financial worries

Table 2 outlines suggested interventions for addressing these symptoms.

Table 2: Examples of Interventions for Navigators Specific to Patients With NSCLC

Intervention	Example
Assessment	Complete Distress Thermometer at each visit and outline options for support
Planning	Based upon known staging and grading, educate patient/caregiver on possible clinical pathways and what might be expected with each treatment pathway Confirm treatment plan with primary oncology care team (eg, physicians, nurses) Begin discussion of advanced-care planning and consider referral to social work
Shared decision-making	Review planned treatment and identify point where new modalities may start or decision points that need to be addressed
Coordination	Maintain ongoing communication with patients, caregivers, and oncology care team Share findings of assessments completed with the care team
Support services	Referrals as needed to social work, genetic counseling, financial navigation, community resources, peer support Identify support groups (eg, in-facility, community, or online/national advocacy groups) Referrals to social work or mental health counseling Identify community resources offering exercise programs geared toward patients with cancer Refer for physical therapy and evaluation as appropriate
Caregiver support	Offer support to patients and caregivers Referral to family counseling Referral to social work or mental health counseling
Spiritual support	Referral to chaplain Identify patient's preferred spiritual support (eg, churches, religion)

NSCLC, non–small cell lung cancer.

Financial and Coverage Issues

Financial toxicity is a major barrier for many patients, exacerbated by the complexity and variability of insurance benefit designs. Even patients with comprehensive insurance may be surprised by unexpected out-of-pocket costs, such as copayments and deductibles. This issue is even more pronounced for uninsured or underinsured patients, who face system-level financial challenges which can delay or limit access to essential care.

Navigators can help reduce financial strain by connecting patients with resources, including social workers, financial counselors, and financial assistance programs. Social workers can guide patients toward publicly funded or industry-supported assistance options to reduce out-of-pocket expenses, while financial counselors can optimize cost-saving strategies by combining multiple aid programs. When in-house resources are unavailable, navigators may need to refer patients to community-based organizations or remotely operated advocacy groups to provide additional financial support.

Transportation, Housing, and Social Barriers

Logistical challenges, such as transportation difficulties, lack of stable housing, and weak social support are common barriers for patients with NSCLC. These issues can disrupt access to appointments and create additional layers of stress. Navigators can assist by identifying available resources to address these barriers, whether through hospital-based programs, local community services, or national organizations providing housing or transportation assistance.

By actively working to resolve transportation and housing challenges and strengthening social support networks, navigators can help patients stay connected to their care team and minimize disruptions to treatment. Addressing these barriers holistically improves the patient’s ability to focus on their treatment and well-being, reducing unnecessary delays and enhancing overall outcomes.

PROVIDER

Care Teams and Variability Across Processes

The complexity and variability of healthcare systems, care teams, and processes can significantly contribute to delays in achieving a definitive diagnosis and initiating timely treatment for patients with NSCLC. These delays may result from a range of factors, including inconsistent referral pathways, communication gaps between providers, and logistical challenges hindering smooth care coordination. Because care pathways often involve consultations with multiple specialists, supportive care services, or second-opinion visits, even minor inefficiencies such as scheduling issues, transportation barriers, or unclear communication protocols can compound over time, further delaying critical steps in the patient’s care journey. These can be further exacerbated when attempting to coordinate with providers outside of the health system. Aspects that may delay care for the patient include all of the above and delays in sharing records and imaging.

In some cases, the preferences, biases, or workload of the referring providers may also impact whether or when necessary referrals are made, adding yet another layer of variability. This inconsistency can leave patients navigating a fragmented healthcare experience, where missed opportunities for timely diagnosis and intervention contribute to unnecessary distress and prolonged uncertainty.

A multidisciplinary care approach is essential to mitigate these systemic delays, but even with such teams in place, patients and caregivers may still feel lost in what can appear to be a confusing and fast-moving process. Here, navigators play a pivotal role. By helping patients manage the logistical challenges associated with referrals and appointments, and by advocating for timely access to appropriate specialists including second-opinion consultations, navigators work to minimize avoidable delays. They can also collaborate with healthcare providers to address systemic bottlenecks, identifying gaps in the referral process and advocating for improvements that streamline care delivery.

Ultimately, by addressing these multifactorial barriers, navigators help enhance the overall efficiency of the healthcare system, ensuring patients with NSCLC are more swiftly guided toward definitive diagnosis and the initiation of treatment, reducing unnecessary delays and improving outcomes.

Inefficiencies of Care

Inefficiencies in cancer care, especially after a diagnosis of NSCLC, can lead to delays and increased stress for patients and caregivers. One major challenge stems from multiple referrals issued in a short time, requiring patients to coordinate numerous appointments across various departments or facilities. Balancing these visits with personal responsibilities such as work, childcare, and self-care can be overwhelming. Navigators help address these barriers by managing the logistics of scheduling, coordinating appointments, and advocating for additional referrals, easing the burden on patients and caregivers.

Care coordination can also become inefficient through gaps within the healthcare system. Even when referrals are initiated, delays may arise due to provider biases, communication breakdowns, or logistical issues like transportation or scheduling. Navigators can streamline this process by facilitating smoother transitions and ensuring timely access to appropriate specialties. By fostering relationships with key professionals across disciplines, navigators help improve care continuity and mitigate system-level inefficiencies.

Another inefficiency involves time constraints faced by healthcare providers, who often struggle to balance patient care with administrative duties. Navigators ease this burden by conducting early assessments to address patients' baseline educational needs and provide resources, reducing the time providers spend on nonspecialty concerns. By acting as liaisons and on-demand resources throughout the care continuum, navigators optimize both the patient experience and provider efficiency, improving overall care delivery.

> Inefficiencies in cancer care, especially after a diagnosis of NSCLC, can lead to delays and increased stress for patients and caregivers

Accessing Clinical Trials

Patients with NSCLC are often eligible for clinical trials, yet many may miss the opportunity to enroll due to educational, social, or logistical barriers. Cancer treatment decisions are already complex, and adding clinical trial participation can feel overwhelming for patients, caregivers, and even healthcare providers. Additionally, patients' perceptions about clinical trials may deter them from participating. Some may fear losing control over their treatment plan in a randomized trial, while others may harbor mistrust of medical research or feel apprehensive about the experimental nature of clinical studies.

Navigators play a key role in bridging these gaps by collaborating with clinical trial nurses and physician investigators to ensure patients are properly evaluated for eligibility. In some settings, navigators themselves may screen patients and initiate discussions about potential trial options. To further enhance understanding, patients can be referred for educational consultations with clinical trial nurses, where they can explore the benefits, risks, and logistics involved in trial participation. By facilitating these conversations, navigators help patients make informed decisions and encourage dialogue with their physicians about whether a clinical trial aligns with their treatment goals. Ultimately, this guidance empowers patients to better navigate the often-intimidating process of clinical trial enrollment, expanding their access to innovative treatment opportunities.

HEALTHCARE SYSTEM

Lack of Resources

The demand for cancer care is rapidly increasing across the United States, placing significant strain on the healthcare system due to more complex treatments, workforce shortages, and rising costs.[3] Effectively navigating patients with NSCLC may require leveraging resources both within the healthcare facility and across external systems to address their diverse needs. Navigators often must find creative solutions to overcome gaps and barriers in the prescribed cancer care pathway. For a more lasting impact, they can collaborate with administrators, physicians, and other key stakeholders, potentially as part of a committee or task force, focused on driving system-wide improvements and enhancing care coordination.

Lack of Reimbursement

Unfortunately, the rising complexity of NSCLC care is not followed by adequate reimbursement. While nurse navigation services can be billed under the Center for Medicare & Medicaid Services Physician Fee Schedule, this usually only applies to direct clinical interventions. Preparatory and educational work is often not reimbursable and take up a significant amount of nurse navigators" time. Often, nurse navigators must come up with creative billing solutions to ensure the time they are putting into caring for NSCLC patients is properly recognized.

Access to Outpatient Diagnostics

Access to outpatient diagnostics can present a significant barrier to care for patients with NSCLC. Timely diagnosis is critical for initiating appropriate treatment, but limited availability of diagnostic services, long wait times, and logistical challenges can delay care. For the health system, the availability of appointments for diagnostic necessities such as positron emission tomograpy scans, magnetic resonance imaging scans, and biopsies can provide significant delay for patients with NSCLC, which may result in disease progression, reduced treatment options, and poorer outcomes. These issues highlight the need for streamlined diagnostic pathways and optimal resource allocation within health systems.

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Planning Treatment for NSCLC

For patients with non–small cell lung cancer (NSCLC), the goal of treatment is 2-fold; to extend the life of the patient and to alleviate the symptoms of disease to enhance quality of life. Both must be balanced when providing care to the patient and be aligned with the goals of care the patient has set out. The navigator plays a critical role in being an advocate for the patient to the healthcare team and promoting a shared decision-making process when working towards goals of care.

Shared Decision-Making

Shared-decision making is integral to the success of the treatment of a patient with NSCLC. It allows the patients to understand the benefits, harms, and impact of the treatment journey they are about to embark on. Furthermore, by involving the patient in the decision-making process and giving them some responsibility in their treatment, patients may be more inclined to be adherent to their therapy and communicate more regularly with their healthcare team.

Quality of life versus quantity of life is an important and highly personal decision to the patient. Different factors such as family responsibilities, age, and culture may play a role into whether a patient values quality or quantity of life more heavily. Healthcare team members often focus primarily on the length of life, but research has shown some patients, particularly older ones, may often value quality of life.[1] While the navigator may provide resources and education for treatment options that lie along the spectrum, it is the ultimate decision of the patient to decide what they want their treatment to entail. Those valuing quantity of life may favor a more aggressive treatment, which will require more education and monitoring on side effects from the nurse navigator. However, some patients may favor quality of life, in which solving practical challenges and perhaps even a palliative care referral will be essential.

In the shared decision-making models, patients with NSCLC have several key responsibilities, including:

- **Sharing information with the treatment team**—Patients should inform their healthcare team about any medications or supplements they are taking and any side effects or symptoms they are experiencing to ensure more effective symptom management
- **Following prescribed treatments and maintaining appointments**—Adhering to medication schedules and attending appointments as recommended by the care team
- **Communicating care goals**—Patients should keep healthcare providers informed about their goals of care, recognizing these goals may evolve over time
- **Sharing milestones and future aspirations**—It is important for patients to communicate milestones and future life goals with key team members so these goals can be integrated into their treatment plan and either achieved during their lifetime or honored in alternative ways after their passing
- **Participating in decision-making**—Patients are encouraged to actively engage in discussions about their treatment, care options, and preferences to make informed choices. It is important to align treatment plans with patient wishes; some may value quality of life over quantity, and the healthcare team needs to be ready to provide various options that best suit the patient's needs
- **Seeking help when needed**—If family members or caregivers interfere with their wishes or care goals, patients should reach out to the healthcare team for support and advocacy
- **Being honest about their needs and concern**s—Patients should communicate openly with their care team about how they are feeling, what worries them most, and what they need—whether spiritually, emotionally, or physically

Multiple models of shared decision-making exist, and every institution may have their own approach. However, a commonly used model is the SHARE model (**Figure 1**), which is a 5-step process of shared decision-making through meaningful dialogue with the patient and family on what matters most to them.[2]

Figure 1: The SHARE Model for Shared Decision-Making[2]

The SHARE Approach

5 Essential Steps of Shared Decision-Making

1 **S** **Seek** your patient's participation.

2 **H** **Help** your patient explore & compare treatment options.

3 **A** **Assess** your patient's values & preferences.

4 **R** **Reach** a decision with your patient.

5 **E** **Evaluate** your patient's decision.

Source: The SHARE Approach. Agency for Healthcare Research and Quality, Rockville, MD. July 2014. www.ahrq.gov/health-literacy/curriculum-tools/shareddecisionmaking/index.html

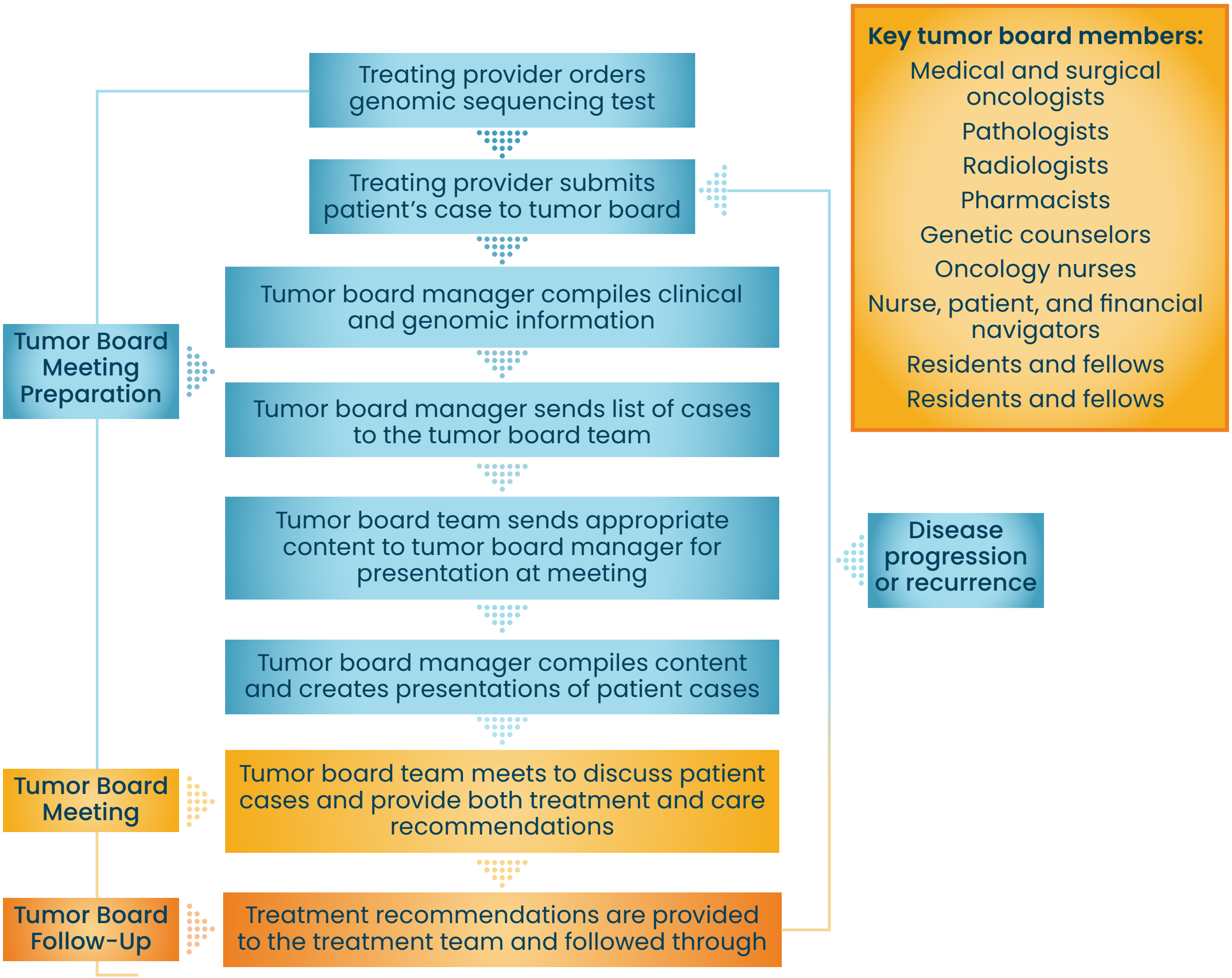
Tumor Board and the Nurse Navigator

A tumor board is essential to providing the best possible care to patients with NSCLC. Multidisciplinary tumor boards are conducted on a regular basis and often include multiple team members including nurses, physicians, navigators, and other extended team members. The goal of a tumor board is to discuss complex cases with all members of the team to ensure a patient is receiving optimized and holistic treatment. Depending on the size of the institution, tumor boards may be divided into different disease states such as breast, lung, or prostate.[3] Some institutions may have molecular tumor boards which focus on discussing molecular biomarkers, appropriate treatments, and clinical trial enrollments.[3]

Tumor boards are often run operationally by a tumor board manager.[4] The manager will follow standard operating procedures to set the meeting agenda, disseminate cases and relevant information to board members, return recommendations, develop documentation, and provide continuing medical education.[4] Guidance documents can be developed in order to standardize responses from board members, making tumor boards more efficient. **Figure 2** shows a model tumor board process.[4]

Once data are provided and the tumor board is convened, the board will go through each case and provide recommendations. Whether all cases, new cases, or selected cases are presented is at the discretion of the healthcare system.[5] The core focus of the navigator in the tumor board should be focusing on ensuring the treatment recommended by the board aligns with evidence-based clinical practice guidelines, the patient's goals of therapy, and is feasible by the patient. Many patients will have both clinical and nonclinical barriers to care, and the nurse navigator will need to be an advocate for the patient in a tumor board. This will include the navigator ensuring the treatment plan aligns with patient's goals of therapy from both the clinical and nonclinical perspectives. For example, clinical trials requiring monitoring at an academic center may not be feasible for a patient living a considerable distance away. Patients may have housing issues or may not have the finances to pay for specialized treatments recommended by providers. In these scenarios, the nurse navigator should bring these barriers to the attention of the tumor board, and work to find the best possible treatment option for the patient. Treatments for patients need to be optimized in terms of clinical

Figure 2: Recommended Process Model for Tumor Board[4]



outcomes and logistics; a treatment plan involving regular monitoring at a distant academic center for a patient with transportation issues will jeopardize the patient's willingness to remain adherent to treatment. It is the responsibility of the nurse navigator to follow up on and communicate to the patient the recommendations being made, and to ensure these recommendations still align with the patient's goals of therapy as they progress through treatment. These recommendations should be communicated with the patient regularly. As recommendations are made, nurse navigators should be on the lookout for opportunities where appointments, testing, or imaging can be scheduled proactively for the patient.

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Treatment of NSCLC

Treatments for non–small cell lung cancer (NSCLC) have significantly evolved in the past few years. Initially, treatment focused on the use of chemotherapy or chemoradiotherapy-type treatments. However, targeted therapies, immunotherapies, and antibody–drug conjugates (ADCs) have recently been coming to the forefront. With the evolution of treatment, the role of the nurse navigator in a patient's treatment will become more pertinent. The navigator and the oncology care team can provide support through shared decision-making strategies, where patients, caregivers, physicians, and other members of the treatment team collaborate to make informed choices about treatment, testing, and overall medical care. This approach ensures patient preferences and personal goals are factored in when determining the most suitable options for each patient. Along with considering the patient's perspective and the cancer treatment plan, it is essential to assess any secondary comorbid conditions and their potential impact on treatment decisions.[1]

Palliative Care

Palliative care has been recognized as an integral part of NSCLC treatment, regardless of the stage of disease. In palliative care, treatment focuses on managing the symptoms associated with cancer and cancer care affecting the patient's quality of life. When symptoms do occur, the type and severity depend on multiple factors including new growths or adverse effects of treatments. Major oncology organizations recommend that physical, psychosocial, and spiritual comfort through palliation be integrated into the care plan for all patients with advanced cancer. This recommendation is backed by clinical evidence from numerous studies.[2,3]

In 2017, the American Society of Clinical Oncology (ASCO) convened members of the ASCO Ad Hoc Palliative Care Expert Panel to update their palliative care guidelines. The resulting publication, "Integration of Palliative Care Into Standard Oncology Care," states patients with advanced cancer should receive dedicated, interdisciplinary palliative care early during their treatment. Essential components of palliative care include the following[3]:

- Building a rapport and fostering a strong relationship with patients and caregivers
- Managing symptoms, distress, and functional status, including pain, shortness of breath (dyspnea), fatigue, sleep disturbances, mood disorders, nausea, and constipation
- Exploring and enhancing the patient's understanding of the disease and prognosis through education
- Assessing and supporting the development of coping skills
- Assisting with medical decision-making, including discussions about healthcare proxies and advance directives
- Coordinating care with other healthcare providers
- Providing referrals to additional care providers when necessary

Relief of symptoms and preservation of quality of life are key goals of palliative care being provided to patients with NSCLC. Symptoms may be physical, emotional, or psychological. Strategies utilized to provide symptom relief or enhance quality of life include:

- Medications: opioid or nonopioid analgesics, medications to aid with side effects of NSCLC treatment, inhaled bronchodilators, cough suppressants, anti-secretion medications at end of life
- Integrative care: massage, physical therapy, relaxation, yoga, cognitive behavioral therapy, counseling

Smoking Cessation

While smoking is a key risk factor for patients to contract NSCLC, there is significant benefit in smoking cessation efforts in patients with NSCLC. A meta-analysis determined that patients who quit smoking on or around the time of NSCLC diagnosis was associated with an improved overall survival (relative risk, 0.77; 95% confidence interval, 0.66-0.90).[4]

Smoking cessation efforts may not always ensure that the patient reduces or quits using tobacco products. For some patients, vaping provides an alternative to smoking to consume nicotine. Some patients may even smoke and vape concurrently. Vaping has become highly popular in recent years and has shown a 4-fold risk of lung cancer in patients who both smoke and vape.[5]

Smoking cessation efforts show both immediate and long-term benefits. In the short term, patients who reduce or quick smoking may see a benefit in improved oxygenation, circulation, breathing, energy, and immune response.[6] Patients may see a benefit in lowered blood pressure and improved cognitive capabilities.[6]

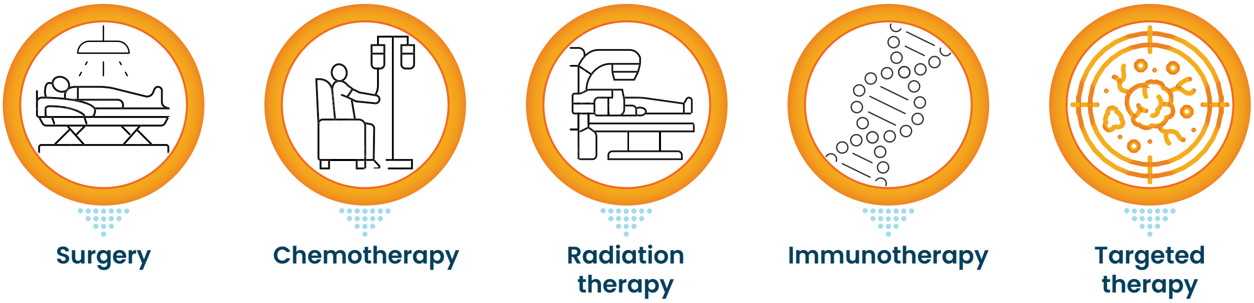
Long-term benefits are more profound. Firstly, patients with NSCLC who quit smoking have a lower risk of disease progression.[6] Patients with NSCLC always have some level of background risk of secondary tumors, whether as a recurrence or an metastases.[6] Compared with the general population, those with NSCLC showed a 3.5-time greater risk of all secondary cancers.[7] For those who were treated with alkylating agents in combination therapies, patients with NSCLC who continued smoking were at a 19-fold greater risk of secondary tumors.[7] Smoking cessation after a diagnosis of NSCLC has been linked to increased survival time. A study of 5229 NSCLC patients demonstrated that current tobacco users with NSCLC had a statistically significantly lower median survival time (1.1 years) compared with those who had never smoked (1.4 years) and former tobacco users (1.3 years).[6] Other long-terms benefits include improved response to chemotherapy and radiation, increased quality of life, and reduced postoperative complications.

As smoking has been shown to have negative survival benefits in patients with NSCLC, and there is a benefit to smoking cessation, it is integral for healthcare providers and nurse navigators to engage in smoking cessation efforts with the patient. Motivational smoking interventions may be necessary.[6] Furthermore, patients with NSCLC who are tobacco users may be more dependent on smoking than the average patient.[6] For these patients, more intensive behavioral interventions combined with pharmacotherapy may be necessary.[6] Pharmacotherapy for smoking cessation includes nicotine replacement therapy, bupropion, or varenicline.[6] Nicotine replacement therapy may be combined with bupropion for certain patients.[6] Other factors for the nurse navigator to consider that may hinder smoking cessation efforts include lack of patient motivation, the presence of a stigma or self-blame, and the smoking status of people the patient is regularly around.[6]

CURRENT TREATMENT PARADIGM

Treatment of NSCLC is highly specific to the patient's disease and goals of care, and can use many different methods (**Figure 1**). In general, earlier stages of NSCLC may be treated through surgical means.[8] However, more advanced disease will most likely require some form of pharmacological intervention.[8] Regardless of the intervention, the nurse navigator will have a key role in guiding the patient through treatment as well as ensuring all barriers to patient care are resolved

Figure 1: NSCLC Treatment Options



NSCLC, non–small cell lung cancer.

Surgical

Treatment of NSCLC from a surgical perspective may use multiple methods based on the individual patient and what is available at the treatment center. In some cases, a thoracotomy, or open lung surgery may be performed. In this scenario, the surgeon will make a large incision at the level of the ribs and resect the malignant part of the lung.[9] Where the incisions are made will depend on the portion of the lung requiring removal.[9] In others, video-assisted thoracic surgery (VATS) may be utilized. Similar to the thoracotomy, this procedure utilizes smaller incisions and utilizes a video camera to allow the surgeon to removed diseased lung tissue.[10] However, as the incision is smaller, there is generally a lower risk of complications and a shorter hospital stay associated with VATS.[9] VATS is recommended primarily for the treatment of early-stage tumors.[9]

For larger centers who have access to the equipment, robotic-assisted thoracic surgery (RATS) may be utilized.[9] In this method, the surgeon sits at a control panel in the operating room and controls robotic arms to operate through several small incisions in the patient's body.[9] RATS is similar to VATS as the level of pain, blood loss, and recovery time is less compared with thoracotomy, and may be preferred if the facility has access to it.[9]

Radiation Therapy

Radiation therapy utilizes high-dose X-rays or a radioactive compound to irradiate the tumor site and kill NSCLC cells.[11] Per NCCN guidelines, radiation therapy is utilized in patients with early-stage disease who are medically inoperable, who refuse surgery, or who are high-risk surgical candidates who have stage IV disease who may benefit from local therapy.[12] However, radiation therapy may also have use for adjuvant, neoadjuvant, or symptomatic relief purposes.[11] For example, patients with NSCLC may be prescribed radiation therapy for palliative intent, whether for obstructive disease, bone or brain metastases, or symptomatic chest disease. To deliver radiation therapy, there are multiple modalities including external beam radiation, (known as stereotactic body radiotherapy, intensity-modulated radiation therapy, or image-guided radiotherapy), proton therapy, or internal radiation therapy (known as brachytherapy or implanted radiation therapy).[11] The procedures themselves last only a few minutes, but most radiation treatments are given 5 days a week for 5 to 7 weeks.[11] Brachytherapy is sometimes utilized to decrease the size of tumors in the airway to provide symptomatic relief.[11] For patients with stage III disease, proton therapy may be used in order reduce the risk of damaging surrounding organs.[11]

Chemotherapy

Before targeted therapies, chemotherapy was the backbone of NSCLC treatment. Now, when targeted therapies are used, they may be used in combination with traditional chemotherapy. Mechanisms of chemotherapy are varied. Some agents may focus on disturbing DNA repair, creating DNA damage, or inducing apoptosis. However, in some way, all chemotherapies focus on stopping cell growth.

Chemotherapy usages may have different goals. For example, neoadjuvant chemotherapy is primarily utilized to shrink tumors down to a point to where they can be surgically resected. NCCN guidelines recommend a variety of treatments for neoadjuvant therapy.[12] For all patients, a platinum backbone utilizing carboplatin or cisplatin may be used. Platinum doublets utilizing these agents in combination with others like gemcitabine, paclitaxel, or pemetrexed may be utilized.[12] For patients who are immune checkpoint inhibitor (ICI) candidates and have advanced disease, platinum agents may be combined with agents such as nivolumab, atezolizumab, and pembrolizumab.[12]

Another goal of chemotherapy may be to use it in an adjuvant setting as a last cleanup of any remaining cancer cells after surgical intervention. Adjuvant chemotherapy may utilize platinum agents and ICIs similar to neoadjuvant treatment.

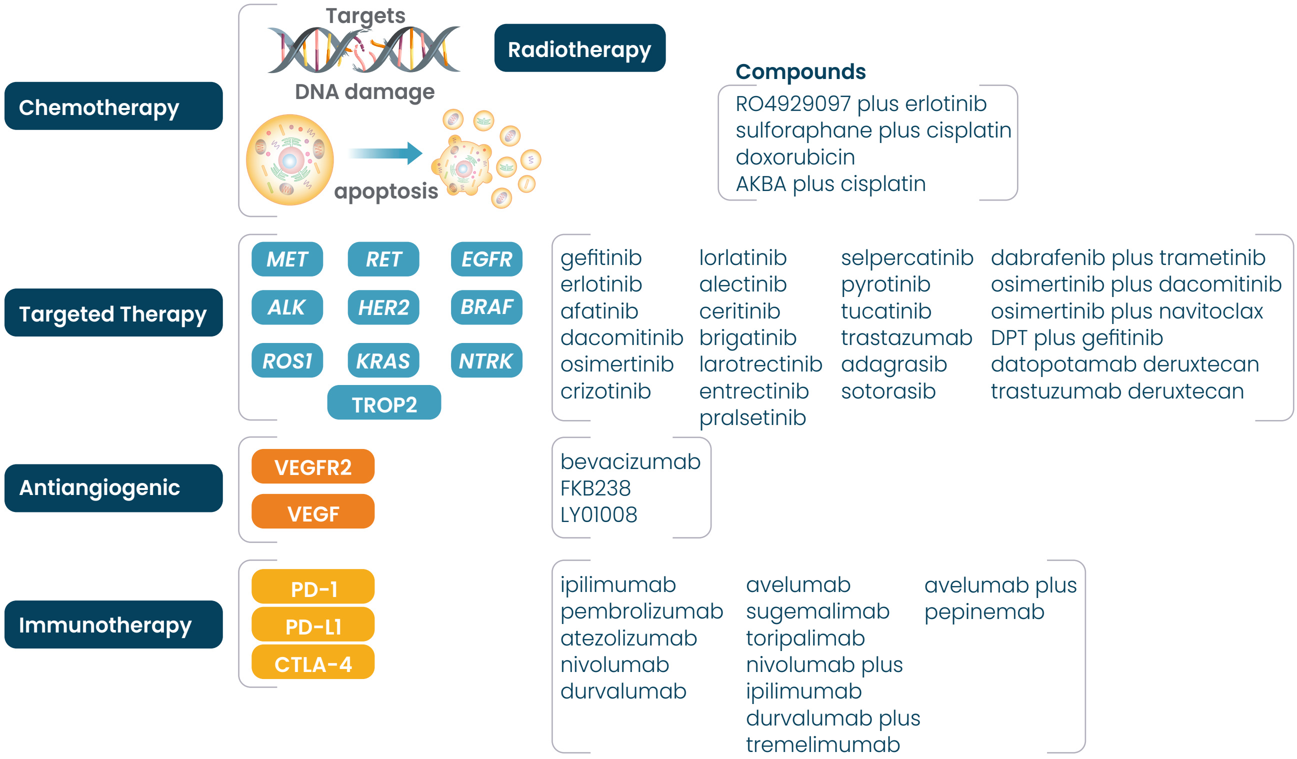
While chemotherapies were the backbone of treatment for many years, there are pitfalls with its use. Firstly, chemotherapies are often nonspecific, and target rapidly dividing cells. While this would make it prone to targeting cancer cells, chemotherapies may target other healthy rapidly dividing cells in the process. Furthermore, though chemotherapies may be effective on initial visits and beyond, the risk of resistance to the agent does exist.[8] When resistance is acquired by NSCLC cells, providers must consider other regimens to ensure the disease does not progress.

Targeted Therapies

Targeted therapies focus on stopping a specific cellular process involved in NSCLC growth.[11] Lung cancer is ultimately driven by oncogenes, which are targetable alterations which provide the chance for targeted therapy.[8] **Figure 2** displays some common targets for both targeted therapies and immune therapies. To utilize targeted therapy, patients with NSCLC must have gene variants confirmed by diagnostic assays.[8] For example, if a patient has an ALK-positive tumor, they would be a candidate for the ALK-targeting tyrosine kinase inhibitor. Diagnostic assays are discussed in the introduction of this toolkit and the role of the nurse navigator is discussed in another section (**Navigators' Role in Biomarker Testing**). Overall, the use of diagnostic and molecular testing methods allows for patients with NSCLC to gain a more precise and personalized treatment, maximizing the cytotoxic effect on cancerous cells while minimizing the effect on healthy ones. This can lead to an overall increased effectiveness and reduced side-effect profile for the patient.

Currently, there are many different targeted therapies on the market.

Figure 2: Targets in the Treatment of NSCLC[8]



NSCLC, non–small cell lung cancer; PD-1, programmed cell death protein 1; PD-L1, programmed death ligand 1.

Immunotherapy

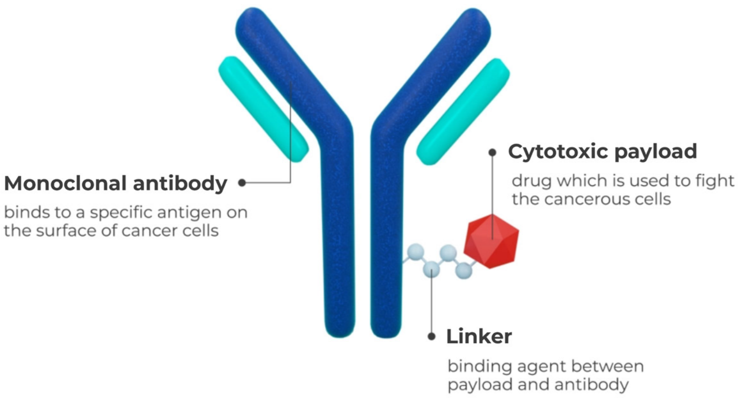
Whereas targeted therapies act on actionable gene variants, immunotherapies focus on utilizing antibodies to mobilize the body's own immune system into attacking cancerous cells.[13] Immunotherapies can be utilized in a variety of different stages of NSCLC treatment, but are most utilized in metastatic or advanced NSCLC. Immunotherapies may also be used in combination with chemotherapies depending on the patient's specific gene variant status. Immunotherapy drug classes commonly used in the treatment of NSCLC include cytotoxic T-lymphocyte–associated protein 4, programmed death receptor 1, and programmed death-ligand 1.

Emerging Treatment Options: ADCs

While chemotherapy, targeted therapy, immunotherapy, and radiation therapy make up the backbone of NSCLC treatment, new options are always on the horizon. ADCs, particularly, have been making waves in NSCLC treatment.

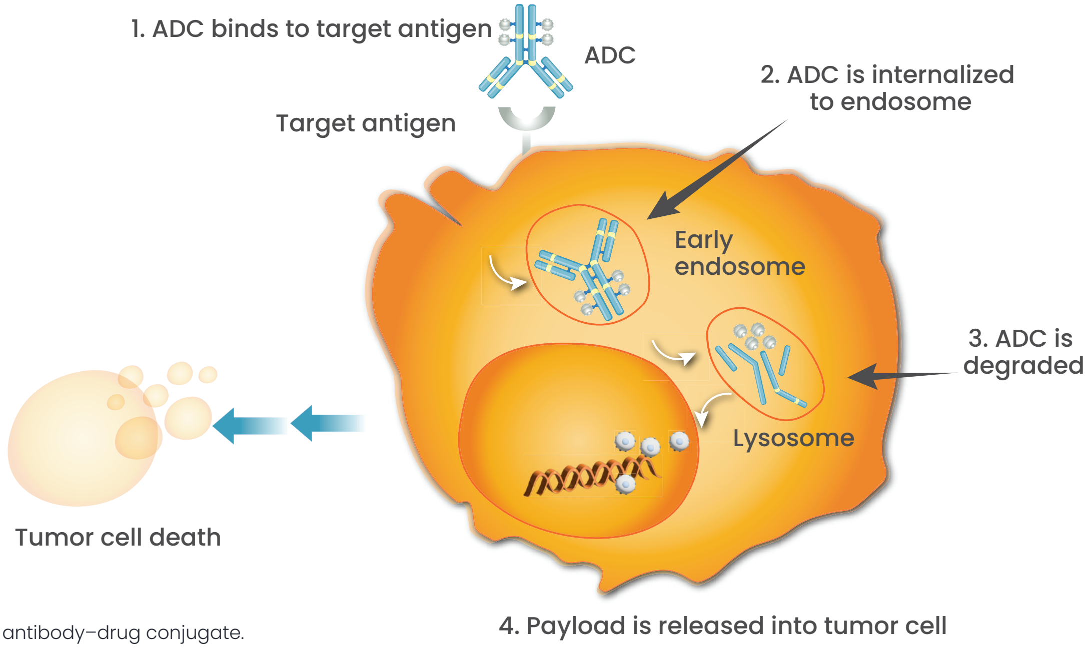
ADCs are like targeted and immunotherapies in that they act on an actionable genetic abnormality. However, ADCs are comprised of 3 parts; a monoclonal antibody targeting a tumor-expressed antigen, a cytotoxic payload, and a cleavable linker (**Figure 3**).[14] Once introduced into the body, if the ADC recognizes the target antigen, it will bind to the target, internalize, and release its cytotoxic payload. This mechanism is displayed in **Figure 4**.

Figure 3: Structure of an ADC[15]



ADC, antibody–drug conjugate.

Figure 4: Mechanism of ADCs[16]



ADC, antibody–drug conjugate.

Certain ADC targets have been well established in the NSCLC space, including HER2, HER3, TROP2, and MET.[16] **Table 2** shows selected ongoing or completed trials utilizing ADCs in NSCLC.

Table 2: Selected Ongoing and Completed NSCLC ADC Trials[16]

Drug	Target	Payload	NCT Number
Anetumab-ravtansine	Mesothelin	Ravtansine	NCT03102320
ARX788HE	*HER2*	Monomethyl auristatin F	NCT03255070
Datopotamab deruxtecan	TROP2	Deruxtecan	NCT04656652
Enapotamab-vedotin	AXL	Vedotin	NCT02988817
Telisotuzumab vedotin	*c-MET*	Vedotin	NCT03539536
Trastuzumab emtansine	*HER2*	Emtansine	NCT02289833
Upifitamab-rilsodotin	NaPi2b	Rilsodotin	NCT03319628

ADC, antibody–drug conjugate; MET, mesenchymal epithelial transition fact; NSCLC, non–small cell lung cancer; TROP2, trophoblast cell surface antigen 2.

The choice of therapy utilized for a patient with NSCLC will not only depend on their gene variant status, but also the patient's values being brought into the shared decision-making process with the rest of the healthcare team.

Clinical Trials

When engaging in shared decision-making discussions, clinical trial participation should be explored as a possible option for patients with NSCLC. As of March 2025, ClinicalTrials.gov, a database maintained by the National Library of Medicine, lists over 7000 ongoing clinical trials focused on NSCLC. These trials investigate a range of tests and interventions including chemotherapy, ADCs, radiation therapy, diagnostics, prognostics, and imaging.

Participating in clinical trials offers patients access to cutting-edge care and innovative therapies, along with close monitoring by a comprehensive healthcare team, including their primary oncology providers. However, while clinical trials present valuable opportunities, challenges remain in enrolling and retaining patients. Furthermore, providers may have differing philosophies regarding clinical trials and their benefits. Understanding the provider's viewpoint on clinical trials and constant communication with the team is crucial to avoiding resistance in enrolling the patient. Overall, navigators can play a critical role in addressing barriers to trial participation, whether from the patient or provider side, and screening patients by matching trial eligibility criteria to a patient's medical history.

Participating in clinical trials offers patients access to cutting-edge care and innovative therapies, along with close monitoring by a comprehensive healthcare team, including their primary oncology providers.

Additionally, timing is crucial when introducing the possibility of clinical trial enrollment. If a patient is distressed or overwhelmed on a given day, it may not be the best moment to have an in-depth discussion about clinical trials. In such cases, the navigator can plan to revisit the conversation later and may involve a clinical trials nurse to provide more detailed information at an appropriate time. **Table 3** discusses some of the issues and barriers associated with clinical trial enrollment and how nurse navigators may intervene, and **Table 4** shows skills essential to the nurse navigators who provide care to patients participating in clinical trials.

Table 3: Issues and Barriers Confronting Patients Enrolling in Clinical Trials

Category	Issue or Barrier
Enrollment is low	Only 20% of US cancer patients qualify for clinical trials Participation rates are as low as 3% to 5% Enrollment is particularly low among minority groups, rural populations, and elderly individuals
Limited awareness of clinical trials	Patients and caregivers may feel uncertain about how to enroll in or participate in clinical trials
Barriers to informed decision-making	Patients and caregivers may struggle to make informed decisions about trial participation due to: Literacy challenges Language difficulties Persistent distress Time constraints Limitations stemming from physical or psychosocial factors (eg, transportation issues or pain) Misconceptions about clinical trials
Financial concerns	Patients may be uncertain about whether other expenses, aside from trial-specific treatments and tests, are covered Financial challenges, such as insufficient support systems or food insecurity, may cause anxiety over potential unexpected costs of the trial
Healthcare team knowledge/ time limitations	Healthcare providers may lack adequate knowledge of trials available to patients Contributing factors include: Limited familiarity with trials for which patients might qualify Time pressures involved in enrolling and managing trial participants

Table 4: Navigator Skills Essential for Supporting Patients in Participating in Clinical Trials

Class of skill	Navigators skills/activities
Trial identification and enrollment	Develop awareness of trials in NSCLC through research and discussions with members of the healthcare team Prioritize educating and supporting patients regarding clinical trials, rather than emphasizing enrollment Offer population-specific peer support to encourage participation among racial/ethnic minorities and other underserved populations
Ensuring informed consent of the patient	Present clinical trial options in a neutral, unbiased manner Approach informed consent as an ongoing process Emphasize the patient's right to decline participation or withdraw from the trial at any time Identify and address any obstacles to informed consent and decision-making by engaging with both the patient and their caregiver Become familiar with the cancer center's policies and procedures related to informed consent Provide support to patients who are considering withdrawing their consent after initially agreeing to participate and discuss the possibility of reconsenting if applicable
Shared decision-making	Facilitate ongoing education to ensure patients stay informed throughout the clinical trial process Stay mindful of ethical considerations and established standards related to clinical trials Encourage patients to communicate any concerns or issues to their healthcare team
Logistical considerations	Help patients address challenges which may impact their continued participation in NSCLC clinical trials, including insurance coverage, transportation, or lodging issues After addressing logistical concerns, ensure there is a long-term plan towards keeping the patient enrolled in the trial
Communications with the healthcare team	Ensure open and consistent communication between the patient, caregiver, and healthcare team Regularly contact the healthcare team to obtain updates on the patient's status while participating in NSCLC trials Ensure the navigator understands the philosophy of the provider regarding clinical trials, and has strategies in place in case they encounter resistance

NSCLC, non–small cell lung cancer.

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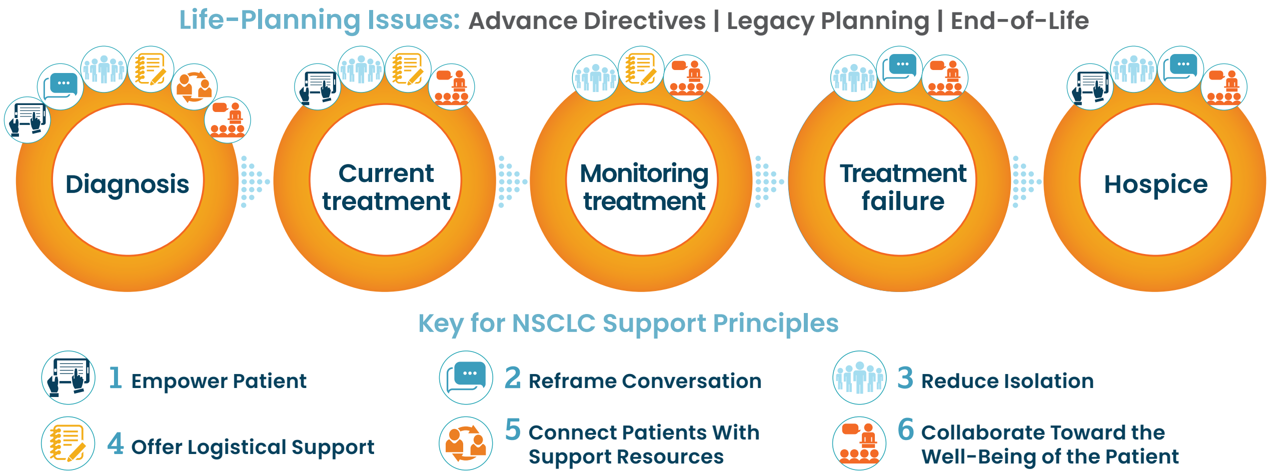
Communication During Treatment

From diagnosis and staging to developing a treatment plan, communication between the healthcare team and patients with non–small cell lung cancer (NSCLC) primarily centers on education. This extends to the patient's families and caregivers. The education process can often be overwhelming for the patient who may be experiencing this disease information for the first time. From the patient's viewpoint, communication may feel largely one-sided, requiring them to absorb a significant amount of information in a brief period. Adding to the stress, patients must come to terms with the reality that this influx of information will deeply affect multiple aspects of their lives and their loved one's lives. Navigators have a key opportunity to foster open communication among all parties involved in the patient's care. This is crucial for gaining a better understanding of how patients are coping with their diagnosis and navigating their treatment decisions. By promoting collaborative communication, navigators can more effectively assess the patient's needs; whether clinical, psychosocial, emotional, or practical. This approach helps to identify barriers to care, enabling the delivery of patient-centered, rather than strictly disease-focused care. Many approaches exist to fostering this relationship, how to communicate with patients, and what the goals should be. One such is displayed in **Figure 1**.[1]

Figure 1: ACCC Communication Process Map for NSCLC[1]



ACCC, Association of Community Cancer Centers; NSCLC, non–small cell lung cancer.

Adherence to Treatment

Adherence involves fully complying with all components of treatment, including attending appointments for radiation and intravenous drug therapy, taking prescribed oral medications, and scheduling regular visits for essential tests to track treatment progress.

Distress can significantly impact a patient's ability to adhere to their treatment plan. For example, a patient with NSCLC who experiences physical pain, social isolation, and mental confusion may skip doses of oral medication. Since distress is common among patients with cancer, it can reduce their willingness or ability to adhere to their prescribed treatment regimen.[3] Types of distress which may negatively impact adherence include[2]:

- Fear and uncertainty about the future
- Concerns about disease and recurrence
- Money or financial stress

- Worries about side effects from the disease or treatment
- Anxiety about family and relationships (eg, as a parent or spouse)

In some cases, patients may avoid sharing the full extent of their side effects or symptoms due to fears their treatment might be discontinued or their dosage lowered. As a preemptive effort to avoid this, the nurse navigator may want to discuss the critical importance of honest communication with the care team, as withholding information can be detrimental and even harmful to the benefit of their treatment.

Clinical navigators also play a key role in reinforcing medical information in a way patients can better understand. They can explain the purpose of specific medications and help patients develop strategies to remember their doses.[3] This is especially relevant as more anticancer drugs are now taken orally with patients managing their treatment at home. While oral medications offer convenience to the patient, they can increase the risk of nonadherence to therapy. PharmDs can be an excellent resource in educating the patient on oral oncolytic therapies, and the nurse navigator should tap into this resource in order to optimize patient outcomes.

> Navigators have a key opportunity to foster open communication among all parties involved in the patient's care.

Addressing and alleviating distress is essential to improving adherence, particularly for oral medications.[2] Other risk factors that may impact adherence include[4]:

- Patient-related factors: limited financial resources due to an inability to work or increased treatment cost
- Psychosocial and cognitive factors: memory issues because of brain metastases
- Disease-related factors: such as the length of time since diagnosis or the severity of the disease

Nonadherence can result from a variety of factors, including those related to the patient, disease, treatment, healthcare providers, and the overall healthcare system. For example patients, caregivers, and healthcare teams may not align on the definition of adherence, causing issues. Regardless of the cause, poor adherence generally leads to worse clinical outcomes.[4]

Two tools nurse navigators may use to assess and improve adherence of oral drugs include the Medication Nonadherence Risk Tool Assessment and the ONS Oral Anticancer Medication Toolkit[5,7]:

Monitoring for Adverse Events (AEs)

Communication with the healthcare team is crucial for monitoring for AEs. While some novel treatments may require step-up dosing or initial hospitalization, ultimately, it will be up to the patient to monitor and report any abnormalities to the healthcare team. Upon initiation of a treatment regimen, patients should be provided with verbal education and written materials on common and serious AEs associated with their therapy. Patients should be guided by the nurse navigator on what they should be on the lookout for, and appropriate items needed to properly manage AEs. Nurse navigators should ensure patients understand how to use monitoring tools properly; patients who have never used thermometers, blood pressure cuffs, or pulse oximeters should be counseled on proper usage.

Some patients may not report adverse effects out of fear of a dose decrease or stoppage. For the nurse navigator, building trust with the patient will be key to ensuring they do report adverse effects, and report them properly. Patients should be provided with a direct number to their nurse navigator, and be encouraged to report even the minor inconveniences, as they may be signs of something more serious. For after-business hours, nurse navigators should have a plan for whom the patient's calls should be directed to. In times such as these, the number of the team member receiving calls after hours should be provided to the patient. Consistent follow-up and reiteration of the importance of reporting adverse events can be critical to avoiding hospitalization down the line.

When a patient reports an AE, it should be documented and relayed to the healthcare team. The nurse navigator may be responsible for being an advocate for the patient, and ensuring their goals of therapy and wishes are being met as the healthcare team works to resolve the AE.

Questions to Ask Your Healthcare Team

As the nurse navigator, guiding the patient through their therapy is the primary goal. To do this, constant communication with the team will be key. Questions you may ask your team members are the following:

- **Physicians:** Is this treatment you are recommending in line with the patient's wishes? Will the patient's life situation allow them to stay adherent on the therapy?
- **Patient navigators:** What barriers do you foresee for patients when they transition to community-based care? How can we best help to avoid those barriers?
- **Hospice care staff:** What is this patient's goals of care? As they approach the end of life, how can we best provide comfort or honor them with dignity?
- **Financial navigator:** Is this therapy covered by the patient's insurance? If not, what can we do to reduce the financial burden?
- **Dietician:** How will this therapy affect the patient's diet, and what options will they have?

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Survivorship

For patients with non–small cell lung cancer (NSCLC), survivorship marks a critical phase of the cancer journey. Advances in early detection, surgery, radiation, adjuvant chemotherapy, targeted therapies, and immunotherapies have led to improved outcomes, but many survivors face a complex array of challenges once treatment concludes. Survivors of NSCLC may experience lingering respiratory and physical issues such as dyspnea, cough, wheezing, neuropathy, fatigue, hearing loss, phlegm, and pain.[1] Quality of life (QOL) and psychosocial issues are also common. Patients with NSCLC when compared with a general reference group showed that 2 years after surgery, physical and mental health-related QOL was lower among the NSCLC cohort.[1] Psychosocial distress is reported in approximately 43.4% of NSCLC survivors, which is higher than the rates seen in other cancers.[2] Nurse navigators play a central role in supporting NSCLC survivors through this transitional period by coordinating care, addressing ongoing concerns, and providing personalized education and resources.

Screening for Other Cancers

Survivors of NSCLC are at an increased risk of developing second primary lung cancer cancers. It is estimated that for patients with NSCLC who underwent resection, there was a 5% risk of second primary lung cancer within the first 3 years, which rises to 16% after 8 years.[4] Prediction of whether a patient will obtain a second lung cancer is difficult, but certain risk facts such as smoking status, older age, and family genetics may increase the risk. Beyond second lung cancers, the risk of other cancers also increases. In general, secondary malignancies among all cancer survivors comprise approximately 15% to 20%.[5] Regular screening for secondary cancers is a critical component of NSCLC survivorship care, enabling early detection, and timely intervention.

Nurse navigators play a key role in developing individualized surveillance plans for survivors of NSCLC based on factors such as smoking history, genetic predispositions, and treatment-related risks. For example, continued low-dose computed tomography screening may be recommended for survivors with a significant smoking history to detect new or recurrent early-stage lung cancers.[6] Other imaging, biopsy, and screening methods may be necessary to provide surveillance for cancers other than lung. Nurse navigators also educate survivors about the importance of adherence to screening schedules and address barriers such as anxiety, financial concerns, and transportation challenges.

> Nurse navigators play a key role in developing individualized surveillance plans for survivors, educating survivors on the importance of adherence to screening schedules, and addressing barriers to adherence.

Survivor’s Guilt

Survivor’s guilt is a common psychological burden among NSCLC survivors, with as many as 55% of patients surviving NSCLC experiencing survivor’s guilt.[7] As treatment outcomes improve and more patients achieve long-term remission or survival, some survivors may struggle with feelings of guilt for having survived while others did not. This emotional distress can lead to anxiety, depression, and social withdrawal, adversely affecting survivors’ mental health and QOL.

Nurse navigators play a critical role in recognizing and addressing survivor“s guilt in patients with NSCLC. By fostering open communication and providing a safe space for survivors to express their feelings, nurse navigators can help survivors process complex emotions and validate their experiences. Cognitive-behavioral therapy is often recommended to help survivors reframe negative thoughts and develop healthier coping mechanisms. Nurse navigators facilitate access to mental health professionals, including psychologists and psychiatrists, who can provide specialized care for cancer survivors.

In addition to individual therapy, peer support groups can be beneficial for NSCLC survivors dealing with survivor's guilt. Connecting with other survivors who have faced similar challenges can reduce feelings of isolation, build resilience, and foster a sense of community. Nurse navigators can recommend local or online support groups tailored to lung cancer survivors, enhancing social support, and emotional well-being.

Fear of Recurrence

Beyond survivor's guilt, patients may worry and have fears of recurrence. The rate of recurrence with NSCLC varies by stage; 5% to 19% of patients with stage I disease experience recurrence, while 24% to 40% of patients with stage III disease experience recurrence.[8] Stresses related to the risk of recurrence are individualized to the patient, but it is important for the nurse navigator to assuage these fears up front.

The nurse navigator may assist the patient with these fears in a multitude of ways. First, empowering the patient by providing education of the risk factors related to recurrence, the probability of recurrence, and the signs and symptoms of possible recurrence will arm the patient with the knowledge to act quickly and effectively if any signs and symptoms are spotted. The nurse navigator can also promote healthy living habits like smoking cessation and exercise to reduce the risk of recurrence, as well as provide the patient with a detailed plan of follow-up, surveillance scans and monitoring, and a plan in case recurrence does occur. All these actions will help to provide practical and emotional support to the patient, ameliorating the fears of recurrence up front.

Returning to Normal Life

For survivors of NSCLC, adjusting to life after cancer treatment can be challenging. Rather than returning to their precancer baseline, survivors often need to adapt to a new form of normal that reflects their posttreatment reality. Practical concerns, such as returning to work, managing finances, and maintaining social relationships, are also important aspects of posttreatment life. Survivors may face challenges related to employment, including reduced physical stamina, cognitive impairments, or concerns about workplace discrimination.

Nurse navigators play a crucial role in helping NSCLC survivors navigate this transition. By providing education on the potential long-term effects of lung cancer treatment, nurse navigators can set realistic expectations and empower survivors to take an active role in managing their health. This may include strategies for managing dyspnea, pacing daily activities to avoid fatigue, and practicing stress-reduction techniques such as mindfulness or meditation. Particularly for reduced stamina and fatigue, it is increasingly important to instill the need for regular physical activity in the patient, even if minimal. Providing resources for the patient to engage in physical activity may also be an option. Nurse navigators may also offer guidance or resources on more practical issues such as helping to obtain workplace accommodations, connecting survivors with vocational rehabilitation services, and providing resources on financial assistance programs.

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Navigation and Supporting Disciplines in the Context of NSCLC

The Academy of Oncology Nurse & Patient Navigators (AONN+) defines the navigation process as "helping patients overcome healthcare system barriers and ensuring they have timely access to quality medical and psychosocial care from before cancer diagnosis through all phases of their cancer experience."[1]

In practice, navigation often involves more than a single navigator advocating for the patient. Instead, it typically includes a team of professionals working together to streamline the process. While some may have "navigator" in their job title, others play equally essential roles within the navigation process. Role delineation is important as many roles share the navigation name (registered nurse/oncology navigators, social work navigators, patient navigators), but have very different roles in providing care for the patient.

Navigation professionals come from diverse backgrounds and hold various licenses and certifications. While clinically licensed navigators are often oncology nurses or social workers, other specialists such as registered dietitians and clinical trial nurses play vital roles in navigation. Nonclinical navigators may hold valuable certifications which enhance their effectiveness, such as the community health worker (CHW) certification or credentials from patient navigator training programs. Though some overlap exists between clinical and nonclinical roles, each offers distinct advantages to patients, families, and the navigation process. The Oncology Navigation Standards of Professional Practice developed by the Professional Oncology Navigation Task Force provide distinct definitions for the different roles involved in oncology nurse navigation[2]:

- **Professional navigator:** A trained individual who is employed and paid by a healthcare-, advocacy-, and/or community-based organization to fill the role of oncology navigator. Positions which fall under the professional navigator category include oncology patient navigators and clinical navigators
- **Oncology patient navigator:** A professional who provides individualized assistance to patients and families affected by cancer to improve access to healthcare services. A patient navigator may work within the healthcare system at the point of screening, diagnosis, treatment, or survivorship or across the cancer care spectrum or outside the healthcare system at a community-based organization or as a freelance patient navigator. A patient navigator may be employed by a clinic or a community-based organization and work throughout the community, crossing the clinic threshold to continue to provide a consistent person of contact and support within the healthcare system. A patient navigator does not have or use clinical training
- **Clinical navigator/oncology social work navigator:** A professional social worker with a master's degree in social work and a clinical license (or equivalent as defined by state laws) with oncology-specific and clinical psychosocial knowledge who offers individual assistance to patients, families, and caregivers to help overcome healthcare system barriers. Using the social work process, an oncology social work navigator provides education and resources to facilitate informed decision-making and timely access to quality health and psychosocial care throughout all phases of the cancer continuum
- **Oncology navigation:** Individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from prediagnosis through all phases of the cancer experience

This section provides examples of various roles and support services within the context of navigating care for patients with non–small cell lung cancer (NSCLC). However, this list is not exhaustive. Additional roles may be identified based on the results of a community needs assessment tailored to your cancer program.

Nurse Navigators

The role of the nurse navigator is clearly defined. However, navigating care for patients with NSCLC comes with unique challenges that require addressing specific program and staff development needs. When working with patients facing NSCLC, nurse navigators may have experience in related specialties such as pulmonology, radiation oncology, medical oncology, thoracic surgery, or neurosurgery. On the other hand, oncology nurse navigators who are new to oncology or nurse navigation can strengthen their expertise through educational programs offered by organizations like the Oncology Nursing Society and AONN+.

As clinically licensed navigators, nurse navigators are equipped to educate, assess, and intervene in ways which address the complex physical and psychosocial needs of patients, as well as those of their families and caregivers. Success in this role is typically measured through clinical outcomes and quality indicators.

> As clinically licensed navigators, nurse navigators are equipped to educate, assess, and intervene in ways which address the complex physical and psychosocial needs of patients, as well as those of their families and caregivers

Navigation models can differ significantly across cancer programs and clinical practices. Some nurse navigators manage the entire cancer care continuum, from diagnosis through treatment and into follow-up care. Others may focus on a specific segment of the care continuum, such as assisting patients from the initial diagnosis through their transition to physicians, the care team, and possibly other navigators.

Regardless of where a nurse navigator works in the care continuum, they often serve as the primary point of contact and advocate for both patients and their families. They help to facilitate communication between the patient and the oncology care team. Consultations with treating physicians and specialists often provide patients and families with a substantial amount of information, which can be overwhelming. Regular follow-ups with the nurse navigator allow for the assessment of any learning needs and provide opportunities to help to clarify or reinforce critical information.

Nurse navigators may be responsible for identifying and addressing any psychosocial or practical challenges that may arise during their assessments. When necessary, they refer patients to other appropriate care team members, including the social work navigator. Ideally, cancer centers employ both nurse navigators and social work navigators, which allows responsibilities to be distributed efficiently. In these settings, nurses primarily focus on resolving clinical issues, while social work navigators assist with psychosocial concerns, insurance matters, and other practical support needs.

Social Work Navigators

To enter the field, social workers must complete a master's-level degree. Those specializing in oncology can further enhance their credentials by obtaining Oncology Social Work Certification. Like nurse navigators, social work navigators hold clinical licenses. Through their expertise with oncology-specific and clinical psychosocial knowledge, social work navigators offer assistance to patients, families, and caregivers to help overcome psychosocial, emotional, spiritual, and healthcare system aspects. Oncology social workers may have access to ongoing continuing education opportunities through professional organizations, such as the Association of Oncology Social Work.

In NSCLC, where the complexity of clinical and logistical needs can be overwhelming, nurse and patient navigators often dedicate significant time to addressing these issues. This makes the role of the social work navigator essential for managing the emotional and practical challenges accompanying NSCLC. Social work navigators help patients cope with practical concerns by serving as additional sources of education and support, providing guidance to help patients understand their treatment plans, and advocating on their behalf with the healthcare team. Social work navigators are also critical in helping patients access financial assistance.

Patient Navigators

Patient navigators who are not clinically licensed provide individualized assistance to patients and families affected by cancer to improve access to healthcare services. They assist patients in communicating with their healthcare providers, ensuring patients have the information they need to make informed decisions about their care. To streamline the care process, patient navigators coordinate physician appointments and medical tests, while simultaneously offering support in areas such as finances, legal matters, social concerns, and practical barriers. Additionally, patient navigators work to identify barriers to care and health disparities within the community and connect patients with resources to address these challenges. Continuing education opportunities for patient navigators are available through organizations like AONN+, the American Cancer Society, and The Alliance of Professional Health Advocates.

Professionals who hold a Community Health Worker (CHW) certification may provide patient navigation services as part of their role. The Centers for Disease Control and Prevention highlights key distinctions between CHWs and patient navigators, including the following[2]:

- Patient navigators are assigned to specific patients, while CHWs typically are not
- Patient navigator duties represent a subset of the broader CHW responsibilities
- Patient navigators may come from a variety of occupational backgrounds
- Patient navigation functions as a role or function, whereas community health work is recognized as a distinct profession

While CHWs may have less direct interaction with individual patients, they can make a broader impact by addressing community-level issues, identifying trends, and evaluating behavior patterns possibly influencing the quality of care.

For patients with NSCLC, navigation services provided by professionals without clinical licenses such as patient navigators working alongside CHWs can provide an effective synergy to the work of clinically licensed navigators. Given the complexity of care for these patients, disease-specific training and education help patient navigators further contribute to professional development in this specialized area.

Financial Navigators

Financial navigators support patients and their families by helping alleviate stress or difficulties associated with the financial aspects of cancer care. Their primary goal is to assist patients in understanding their out-of-pocket costs and explain what may or may not be covered by their health insurance plans. They can provide additional services, such as setting up payment plans, identifying cost-saving options for treatment, and improving access to necessary healthcare services. Financial navigators can pursue continuing education through organizations like AONN+ or the Association of Community Cancer Centers (ACCC).[3]

For patients with NSCLC, care plans are often complex and carry a significant risk of financial strain. This burden may not always be fully addressed by nurse, social work, or patient navigators. Professionals trained in financial navigation can make a meaningful difference in patients' quality of life by reducing or preventing the distress possibly arising from the cumulative costs of cancer treatment throughout the care continuum.

Cancer Rehabilitation Team

Although often linked with cancer survivorship, cancer rehabilitation services can benefit patients with NSCLC, as treatments may lead to physical, psychological, and cognitive challenges requiring adaptation by the patient. Rehabilitation may take various forms such as physical rehabilitation, pulmonary rehabilitation, or even cognitive rehabilitation. A variety of specialties are listed below that the nurse navigator may connect the patient to based on their individual need[4]:

- **Physical therapist (PT):** PTs specialize in improving or restoring mobility and can assist in reducing or eliminating pain. Oncology PTs focus specifically on cancer patients and survivors
- **Physiatrist:** Also known as physical medicine and rehabilitation specialists, physiatrists specialize in the prevention, diagnosis, and treatment of nerve, muscle, and bone disorders that can affect movement and function. They frequently work with patients on pain management
- **Cognitive psychologist:** Cognitive psychologists, or neuropsychologists, are experts in understanding how behavior is connected to brain function. They are often involved in managing "chemo brain," a term used to describe cognitive issues cancer patients experience during and after treatment
- **Exercise physiologist:** Exercise physiologists assess a person's fitness to improve their function. They may utilize tools such as stress tests to evaluate cardiovascular health and metabolism. They create customized fitness plans for patients to support them during and after cancer treatment

In tandem with cancer navigation, the cancer rehabilitation team plays a crucial role in overcoming barriers to recovery. For patients with NSCLC, the navigator may consider referring them to cancer rehabilitation before treatment begins. This allows for an assessment of their baseline strength and mobility, aiding in effective monitoring throughout and beyond treatment, and addressing issues early before they worsen. For instance, PTs, cognitive psychologists, and dietitians can be invaluable resources for patients undergoing treatment due to the risks of fatigue, muscle weakness, and cognitive challenges. Physiatrists can be a vital part of the pain management team for symptomatic patients with NSCLC.

Peer Programs and Support Groups

Peer support provides an essential element of care not directly offered by the healthcare team, bringing the unique benefit of firsthand patient experience. One significant concern for those facing the initial diagnosis of NSCLC is the uncertainty of not knowing what to expect. Learning from others who have experienced or are currently undergoing similar challenges can significantly alleviate or prevent distress through shared experiences. Navigators, physician offices, or community organizations may create and maintain lists of patients willing to connect with others for peer support, often referred to as "buddy programs."

> A professional member of the navigation team should orient new "buddies" about their role and the boundaries of providing peer support

To serve as a buddy, individuals should undergo formal training and be covered for liability by the healthcare group or institution they represent. It is important for those seeking peer support to understand the support offered is not medical advice but rather a sharing of personal experiences with diagnosis, treatment, and aftercare. A professional member of the navigation team should orient new "buddies" about their role and the boundaries of providing peer support. Ongoing feedback from both the buddies and the patients they assist should be gathered to ensure the quality of the support being offered.

Peer support can take place in person through individual visits, phone calls, and moderated live support groups. Online support groups and discussion boards can be beneficial when properly supervised and moderated by an appropriate professional.

Clinical Trials Team

Over the past 2 decades, treatment advances have significantly extended the lives of individuals with NSCLC, advancements that would not have been possible without innovations through clinical trials.

However, many patients with NSCLC who could benefit from clinical trials may not be evaluated for or enrolled in these studies, often due to a lack of awareness by both patients and physicians. This creates an undiscovered barrier for those involved. Clinical trial nurses and coordinators, who are often the core of the clinical trial team, play a key role in helping navigate patients past these barriers and provide patients the option to participate in trials that align with their circumstances.

Other factors possibly preventing patients from joining clinical trials include housing instability, lack of phone or internet access, health insurance issues, citizenship or legal residency status, treatment for comorbidities, limited English language skills or literacy, and fear or mistrust of clinical research. Once in a clinical trial, patients may face barriers hindering their continued participation, such as practical issues like transportation, childcare, or work schedules.[5]

In addition to providing education or referrals, the navigator's role regarding clinical trials is to help patients understand them, foster interest, and remove barriers to initial enrollment or ongoing participation. While the decision to enroll in a clinical trial ultimately rests with the physician, the navigator's role includes supporting patients by providing essential information about clinical trials and how they relate to patient care.

Registered Dietitian

A registered dietitian is a health professional with a master's-level education and specialized training in diet and nutrition. They provide guidance on nutrition and healthy eating to help prevent and manage conditions such as food allergies, diabetes, heart disease, and cancer. Dietitians offer services like nutritional counseling, meal planning, medical nutrition therapy (such as special diets, dietary supplements, and intravenous/tube feedings), and nutrition education programs.

Dietitians that specialize in oncology have expertise in addressing complex nutritional issues, particularly for patients with NSCLC. Treatment for NSCLC can negatively impact appetite, eating habits, and weight, making it vital for patients to maintain a healthy weight and consume essential nutrients while staying as physically active as possible. During intensive treatments or multiagent therapy, regular assessments by a registered dietitian can help the patient, caregivers, and healthcare team adjust to changing nutritional needs. Working with an oncology dietitian to navigate diet and nutrition enables patients to take an active role in managing their cancer care.[6]

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End-of-Life Care

End-of-life or hospice care is frequently mistaken for palliative care. While palliative care is provided across different stages of the cancer care continuum, end-of-life care represents the final stage of the disease trajectory. Palliative care may transition into end-of-life care, which may include additional services for the patient. Navigators play a crucial role in improving the quality of life for patients with non–small cell lung cancer (NSCLC) as well as their families and caregivers in what is often a highly distressing time.

Transitioning to End-of-Life Care

The shift from palliative or any other form of care to end-of-life care can be especially challenging. Palliative care referrals may be appropriate as early as the time of diagnosis, even when curative cancer treatments are being pursued. However, end-of-life care applies only when a patient is expected to have ≤6 months to live and has stopped receiving all anticancer treatments. Navigators assisting patients with NSCLC can help facilitate the transition through palliative care and into end-of-life care. Understanding the differences between these 2 forms of care allows navigators to better guide patients and their families in accessing the appropriate resources when needed.

End-of-life care is provided by a specialized team which commonly includes a hospice physician, a nurse trained in end-of-life care, and a social worker as the core members. Under hospice care, additional services that may be provided include:

- Physician services (patients may select 1 primary care physician to oversee their hospice care)
- Nursing care
- Medical equipment and supplies related to the terminal illness
- Medications for managing pain, symptoms, and comfort
- Hospice aide services
- Physical and occupational therapy
- Social work services
- Dietary counseling
- Spiritual counseling
- Bereavement support

One condition for receiving hospice benefits is patients must stop pursuing curative or life-sustaining cancer treatments. These treatments and services, which are generally no longer covered under hospice care, include:

- Inpatient hospital stays for life-sustaining interventions
- Diagnostic procedures (eg, X-rays, lab tests, computed tomography scans)
- Emergency department visits
- Specialist consultations
- Outpatient services
- Ambulance transport

To qualify for hospice or end-of-life care, a physician must certify the patient has a life expectancy of ≤6 months, and this requires at least 1 face-to-face visit during each of the initial 2 90-day certification periods. For patients who live beyond 6 months, recertification is required every 60 days, based on a face-to-face evaluation.

Occasionally, some patients recover unexpectedly and no longer need hospice services, at which point they may resume their previous care plans. However, it is possible for patients to be eligible for hospice before a referral is made. Barriers to timely referral may include physicians overestimating a patient’s prognosis or patients and families struggling to accept the need for hospice care.

Navigators can help address these challenges by having open, honest conversations with patients and their families about end-of-life care and offering them valuable support during this critical stage of the NSCLC journey.

Goals of End-of-Life Care

The primary aim of end-of-life care is to enhance the quality of life for individuals in the final stages of an incurable disease. End-of-life care takes a comprehensive approach, focusing on alleviating various forms of suffering, including physical symptoms, psychological and social distress, and spiritual pain. By reducing and preventing suffering, end-of-life care helps patients manage personal matters and devote more energy to spending time with family and friends.

> End-of-life care goes beyond the patient's death by offering ongoing support to the family. After-death care for the family is an essential part of the cancer care continuum

Pain relief is often a patient's initial concern when thinking about physical comfort. However, discomfort can also arise from emotional and mental strain. Patients receiving end-of-life care frequently face specific fears, such as anxiety about the unknown, concerns for those they will leave behind, fear of dying alone, or worries about how their loved ones are coping. Spiritual needs at end-of-life can be just as significant as physical and emotional needs, as patients often seek to find meaning in their lives, resolve issues with loved ones, or struggle with matters of faith.

Alongside supporting the patient and caregiver in a clinical sense, end-of-life care addresses practical needs which can have a profound impact on the quality of life. Helping with daily tasks, such as collecting the mail, doing laundry, feeding pets, driving children to activities, or picking up medications, can offer caregivers a break and time away from caring for the patient. Keeping close family and friends informed can be overwhelming for both patients and families. To ease this burden, patients and families may set up a voicemail message, an email list, a private Facebook page, or even a phone tree. Some families create blogs or websites to share updates, thoughts, and wishes.

End-of-life care goes beyond the patient's death by offering ongoing support to the family. After-death care for the family is an essential part of the cancer care continuum.

A peaceful death can be defined in many ways, but generally will involve:

- Minimization of distress and suffering for the patient, family, and caregivers
- Ensuring activities surrounding and after death align with the patient's and family's wishes and values in accordance with the cultural and ethical beliefs

Several key factors contribute to a peaceful death and should be discussed when a patient's prognosis indicates they have ≤6 months to live. These factors include[1]:

- Knowing your life had purpose and it was valued by at least 1 other person
- Leaving a legacy unrelated to money
- Having all financial and legal affairs in order
- Leaving no financial debt from cancer care for the family
- Giving and receiving forgiveness
- Being free from pain
- Dying with dignity in a preferred environment
- Feeling confident you will be remembered fondly after you are gone
- Feeling spiritually connected to a higher power

Patients require access to resources to achieve these goals. Simply telling a patient to organize their affairs is not sufficient. They need practical resources to address matters such as financial and legal preparations.

After-death care interventions focus on supporting the family and caregivers, as well as healthcare professionals. Family and caregivers should receive immediate support after the patient's death, including:

- Informing family members of the death
- Offering condolences
- Ensuring respectful and culturally sensitive treatment of the body
- Addressing concerns regarding organ donation or autopsy

Bereavement support for family and caregivers may include:

- Formally expressing condolences through written or spoken means
- Referring to appropriate bereavement services available within the institution or community
- Offering the option of attending a debriefing meeting with the family, if desired

Roles and Responsibilities of the End-of-Life Care Team

In line with the goals of end-of-life care, the responsibilities of the care team are centered on meeting the physical, emotional, mental, spiritual, and practical needs of both the patient and their family during the final phase of life and into bereavement. As the patient transitions from palliative to end-of-life care, the roles of the care team may undergo a shift, with the hospice team taking a more prominent role compared with the primary oncology team.

The hospice care team, which includes professionals with specialized expertise in end-of-life and hospice care, becomes responsible for managing the specific needs associated with this phase. This team is composed of an interdisciplinary group, which may include physicians, nurses, social workers, chaplains, and other specialists who focus on providing comprehensive care tailored to the patient's end-of-life needs. Their involvement ensures the patient's suffering is minimized, and the family receives support in managing the emotional, spiritual, and practical challenges during this time.

> Continued involvement of the entire spectrum of care providers from primary care, oncology, and specialized palliative and hospice services is essential to ensuring a compassionate and effective approach to end-of-life care

The roles and responsibilities of the end-of-life care team are also dynamic, evolving with the patient's condition and specific needs. However, the continued involvement of the entire spectrum of care providers from primary care, oncology, and specialized palliative and hospice services is essential to ensuring a compassionate and effective approach to end-of-life care.

The Navigator's Role in End-of-Life Care

Nurse navigators who assist patients with NSCLC and their families play a crucial and consistent role in facilitating a smooth transition into the final stages of life and through bereavement. As the patient progresses through the end-of-life stages, the nurse navigator provides varying levels of education, support, and advocacy based on the life expectancy of the patient. It is important for navigators to regularly review the key elements of a good and peaceful death to ensure each component is effectively addressed.

Nurse navigators also play a vital role in facilitating discussions about advance directives and healthcare power of attorney by educating patients on their importance in ensuring medical decisions align with their personal values and preferences. They help patients understand the options available, provide guidance on completing necessary forms, and address any questions or concerns. Nurse navigators act as advocates, encouraging early planning to reduce family stress and ensure clarity during critical moments. Through communication with the healthcare team, they ensure documented directives are accessible and honored during treatment. This proactive support empowers patients to make informed decisions and promotes continuity of care.

In the context of NSCLC, nurse navigators are uniquely positioned to significantly enhance end-of-life care. They can inform patients about the expected course of care, including guiding them from active cancer treatments through supportive palliative care and into end-of-life or hospice care. Additionally, navigators offer valuable support to families as they transition into bereavement care following the peaceful death of the patient.

As the acuity of the patient increases during this phase, various healthcare providers and specialists become involved. Nurse navigators can play an important role in ensuring effective collaboration and communication among the different members of the care team, further contributing to a comprehensive and coordinated approach to care.

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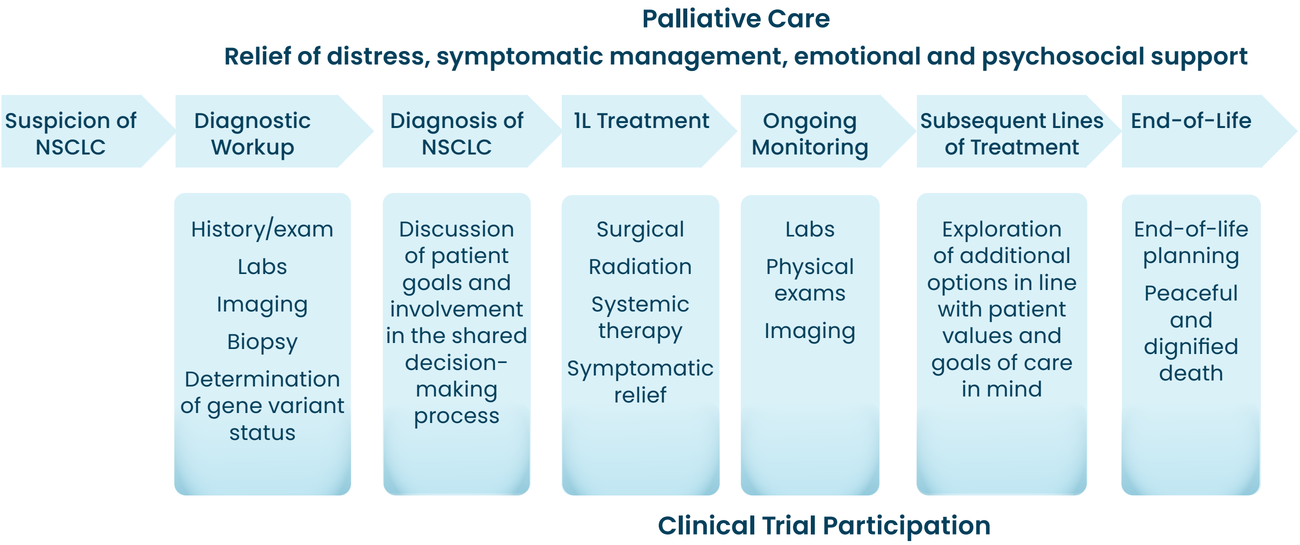
Putting It All Together: Continuum of Care for Patients With NSCLC

The journey of a patient with non–small cell lung cancer (NSCLC) encompasses various stages and phases, from diagnosis to survivorship to end-of-life care. A nurse navigator guides the patient with NSCLC through the continuum of care, including diagnosis, initial treatment, subsequent therapies, participation in clinical trials, and survivorship or end-of-life considerations (**Figure 1**).[1,2] For each patient, this journey is unique, lasting several years for some and only a few months for others. The nurse navigator plays a crucial role at every point along the cancer care continuum.

> The role of the nurse navigator is integral to every step of the NSCLC care continuum, as well as survivorship beyond treatment

Care for patients may differ based on whether they are initially diagnosed with localized or metastatic disease. The general principles of the pathway including diagnostics, treatment, and monitoring will be relatively the same, but may be more intense for those with metastatic disease.

Figure 1: NSCLC Continuum of Care[1]



Palliative Care
Relief of distress, symptomatic management, emotional and psychosocial support

Suspicion of NSCLC	Diagnostic Workup	Diagnosis of NSCLC	1L Treatment	Ongoing Monitoring	Subsequent Lines of Treatment	End-of-Life
	History/exam Labs Imaging Biopsy Determination of gene variant status	Discussion of patient goals and involvement in the shared decision-making process	Surgical Radiation Systemic therapy Symptomatic relief	Labs Physical exams Imaging	Exploration of additional options in line with patient values and goals of care in mind	End-of-life planning Peaceful and dignified death

Clinical Trial Participation

1L, first-line; NSCLC, non–small cell lung cancer.

Role of the Nurse Navigator in the Continuum of Care

The role of the nurse navigator is integral to every step of the NSCLC care continuum, as well as survivorship beyond treatment. Aside from the clinical duties, nurse navigators will constantly be educating patients and being an emotional resource patients can lean on for support. Listed below are just some of the responsibilities of nurse navigators divided by the steps in the continuum of care (**Table 1**).

Table 1: Role of the Oncology Nurse Navigator in the NSCLC Continuum

Step	Roles and responsibilities
Screening	Recommending patient for low-dose CT scans Assessing history and risk factors to determine need for screening Assisting with care coordination for high-risk patients
Diagnostics and workup	Scheduling of labs, imaging, and biopsies Educating the patient on results of above, and impact on treatment Ordering and following up on gene variant testing Providing or interpreting results for the rest of the healthcare team
Diagnosis	Educating patient on NSCLC, including stage, their specific gene variants, and treatment options Development of treatment goals that fall in line with patient values Advocating for an optimized treatment regimen in tumor boards that will best fit the patient Involving the patient in the shared decision-making process
Treatment (first-line and subsequent lines)	Scheduling of radiation, systemic, or surgical therapies Educating patients on therapies, including adverse effects, home monitoring, when to report AEs, and when to go to the emergency department Assessing symptoms of disease or treatment, and recommending symptomatic relief to the HCP Providing recommendations for clinical trials or discussing eligibility with the rest of the healthcare team
Ongoing monitoring	Scheduling of labs, imaging, and exams Educating patient on notable findings Relaying information from monitoring to the healthcare team
End of life	Discussing palliative and end-of-life care with patients and family members Developing goals of end-of-life care Assisting patient with getting personal and legal matters in order Referrals to additional services the patient may need
Survivorship	Assessing the patient for additional screening of secondary cancers Providing resources toward resolving practical issues such as finding work or housing Assisting patient with feelings of survivor’s guilt, or referring to a specialist or peer-to-peer support group

CT, computer tomography; NSCLC, non–small cell lung cancer.

Case

AB is a newly diagnosed NSCLC patient identified through a low-dose computed tomography scan as having a suspicious Lung-RADS 4A finding and was referred to the nurse navigator. Based on the result, the nurse navigator communicated with the pulmonary team using Secure Epic Chat, and learned the patient was scheduled for a pulmonologist appointment within 7 minutes of receiving the results. The nurse navigator then contacted the patient to discuss the results.

Despite the patient's emotional challenges with her mother recently passing away, the nurse navigator provided compassionate support, listening to her concerns and motivating her to attend the pulmonologist appointment and proceed with a biopsy. This led to the diagnosis of stage I NSCLC (adenocarcinoma). The nurse navigator coordinated the patient's case discussion at the lung tumor board, where surgery was recommended. The patient underwent a successful lobectomy and became cancer-free from her lung cancer.

Later, the patient was diagnosed with breast cancer, which she attributed to stress. Throughout this process, the nurse navigator continued to provide emotional and practical support, even stepping into a social worker role when needed. Their relationship culminated in a reunion at a support group, where the patient expressed gratitude to the nurse navigator and her primary care physician, stating that their guidance had been instrumental in the detection and treatment of both cancers.

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Developing an NSCLC Navigation Program

A non–small cell lung cancer (NSCLC) navigation program is typically built upon an existing generalized or disease-specific navigation program. A community-needs assessment may have identified barriers to care that can be most effectively addressed through a navigation program tailored to patients with NSCLC. Since many of the core components are already in place in other disease management programs, launching an NSCLC navigation can be done relatively fast. This enables the program to more effectively meet the needs, priorities, and resource requirements specific to the NSCLC patient population.

The initial development of the program should involve key stakeholders from the NSCLC setting including focus groups with patients, families, and community members. It should also incorporate insights from colleagues in other care systems who have already created and managed similar navigation programs for other disease states.

> The initial development of an NSCLC navigation program should involve key stakeholders from the NSCLC setting including focus groups with patients, families, and community members

Role Delineation

When establishing a new oncology navigation program, the core planning team typically includes a physician, an administrator, and an oncology nurse. It is ideal for members of the core team to have some experience in navigation. Patient navigators, social workers, and other support service providers are added as the program continues to develop. As shown in **Figure 1**, the multidisciplinary cancer care team can include a wide range of members.[1] Depending on the needs and goals of the NSCLC patient population, different team members may serve as experts at various points along the care continuum, with the oncology nurse navigator or oncology patient navigator facilitating collaboration between the team members as necessary.

Before launching an NSCLC navigation program, it is essential to clearly define each role so tasks can be appropriately assigned and delegated as the program is fully developed. Detailed roles and responsibilities of various navigators can be found in **Navigation in the Context of NSCLC.** Overlap in tasks, or "scope creep" is highly common in navigation. While there may be some overlap in tasks, clear role delineation and understanding the roles and responsibilities of each navigator is crucial to optimize care for patients, manage workload of staff, and promote synergy between the healthcare team members. Many models of navigation exist, but for example, role delineation between navigators may be as follows:

- **Nurse navigators:** primarily responsible for the clinical aspects of patient care navigation including patient education, ordering and follow-up of testing, and communicating with the healthcare team
- **Screening navigators:** primarily responsible for facilitating cancer screening processes, including patient education about screening eligibility and procedures, coordinating the scheduling and follow-up of screening tests, ensuring timely communication of results, and collaborating with the healthcare team to guide patients through next steps based on screening outcomes
- **Social work navigators:** primarily focuses on the emotional and practical challenges accompanying NSCLC care
- **Patient navigators:** may assume operational responsibilities such as coordinating physician appointments and medical tests, and connecting patients with appropriate resources based on their individual clinical, financial, or practical needs
- **Financial navigator:** working with the patient to understand out-of-pocket costs and insurance coverage as well as being a resource to find financial assistance if necessary

Figure 1: Patient-Centered Multidisciplinary Cancer Care Team in NSCLC[1]

Source: Franklin EF, House L, Glidden E. Understanding role delineation of the multidisciplinary team members. In: Shockney LD, ed. *Team-Based Oncology Care*: *The Pivotal Role of Oncology Navigation*. Cham, Switzerland: Springer International Publishing AG; 2018:276.

Using the Oncology Nursing Society (ONS) Oncology Nurse Navigator Competencies, which were last updated in 2024, role definition can assist in creating job descriptions for the core positions within the program. The competency categories for both oncology nurse navigators and oncology patient navigators include, but are not limited to[2]:

- Care coordination
- Communication and interpersonal skills
- Patient education
- Professional and organizational development

The AONN+ knowledge domains, outlined in **Table 1**, offer a framework for developing metrics to assess outcome measures in oncology navigation.[3] These are crucial for further defining and refining roles during the program's development and ongoing maintenance.

Table 1: AONN+ Knowledge Domains

Community Outreach and Prevention
Coordination of Care/Care Transitions
Patient Advocacy/Patient Empowerment
Psychosocial Support Services/Assessment
Survivorship/End of Life
Professional Roles and Responsibilities
Operations Management/Organizational Development/ Healthcare Economics
Research/Quailty/Performance Improvement

AONN+, Academy of Oncology Nurse & Patient Navigators.
Source: Strusowski T, Johnston D. *J Oncol Navig Surviv*. 2018; 9:214-221.

For nonclinical patient navigators, The George Washington University Cancer Institute's Core Competencies for Non-Clinically Licensed Patient Navigators detail 8 domains that may be utilized by patient navigation stakeholders in the training and development of patient navigators.[4]

- Patient care
- Knowledge for practice
- Practice-based learning and improvement
- Interpersonal and communication skills
- Professionalism
- Systems-based practice
- Interprofessional collaboration
- Personal and professional development

Navigator Competencies

Selected oncology nurse navigation competencies developed through the collaboration of the ONS and Oncology Nursing Certification Corporation are shown below. These may be helpful to early program development and to creating job descriptions for navigators. Another valid resource to utilize would be the professional standards set forth by Professional Oncology Navigation Task Force.

Care Coordination

- Assess the need for and facilitate educational discussions with patients, support systems, and colleagues
- Support a smooth transition of patients across screening, diagnosis, active treatment, survivorship, palliative care, or end of life, working with the interprofessional team
- Coordinate care, ensuring that the patient is receiving the right care, seeing the right provider or team member, and receiving timely care

Coordination of care is crucial for patients with NSCLC, often necessitating the swift and efficient scheduling of appointments across multiple departments. Patient navigators may primarily handle logistical and administrative tasks, while nurse navigators tend to focus more on education and counseling, especially in relation to palliative care and end-of-life matters. Understanding the role of navigation throughout the cancer care continuum is highly valuable during program development, particularly as roles and job descriptions are being established.

Communication and Interpersonal Skills

- Communicate with patients and their support systems in a culturally sensitive manner, acting as a liaison between the patients and their support systems and other healthcare professionals, for holistic culturally appropriate care
- Provide anticipatory guidance and manage expectations to assist patients and their support systems in coping with a potential or actual diagnosis of cancer and expected outcomes

- Communicate effectively with patients, their support systems, and the public to build trusting relationships across a broad range of socioeconomic and cultural backgrounds

Nurse and patient navigators must have strong communication skills to effectively support patients and families affected by NSCLC. By building trust with the patient in an empathetic manner, navigators can enhance quality of life and patient satisfaction. Additionally, fostering constructive communication with other healthcare team members in the potentially high-stress environment of NSCLC care is essential for ensuring quality care and successful program development.

Patient Education

- Identify patients and their support systems' knowledge gaps in how to manage their own health conditions
- Develop forms and documentation that use health literacy best practices to maximize patients" and their support systems' understanding
- Provide patients and their support systems with evidence-based information to support understanding and decision-making at all points from the cancer diagnosis throughout the care continuum

Anticipating the educational needs of patients with NSCLC, their families, and caregivers is a key responsibility navigators can take on. This is coupled with understanding provider preferences. With a solid understanding of the complex clinical pathways associated with NSCLC, navigators can curate educational resources specifically tailored to this patient population. Navigating the complexities of medical terminology and treatment decision-making can be overwhelming without dedicated support; nurse and patient navigators play a crucial role in simplifying this process.

Professional and Organizational Development

- Contribute to oncology program development, implementation, and evaluation within the healthcare system and community
- Identify, participate, and/or lead quality improvement initiatives to develop, share, and report outcomes of the oncology nurse navigation program to relevant stakeholders
- Mentor, onboard, and educate new oncology nurse navigators and team members about the role

Expert oncology nurse navigators and oncology patient navigators are often equipped with all the necessary tools to create programs that enhance the cancer care navigation process. As the program expands, these experts can mentor new team members, including nurse and patient navigators as well as administrative staff. At times, expert oncology nurse navigators and oncology patient navigators may need to take on more administrative responsibilities to help advance the program. This could involve tasks such as marketing, measuring outcomes, quality control, community outreach, philanthropy, and other high-level duties. Ideally, the program would have both an expert oncology nurse navigator and an expert oncology patient navigator, allowing for a team-based leadership structure which drives the development of the NSCLC program. The expert oncology nurse navigator would focus on clinical tasks and outcomes, while the expert oncology patient navigator would handle administrative and logistical matters. Experienced oncology nurse navigators and oncology patient navigators should strive to operate at the highest level within their scope of practice, especially in a program addressing the complexities of NSCLC patients.

Metrics

Above all, patient outcomes are crucial in nurse navigation. However, it is also important to be able to measure the success of navigation programs in regard to key healthcare system priorities. These may include clinical excellence, resource management, and revenue enhancement.

AONN+ has published a set of 35 standardized metrics measuring the success of navigation programs regardless of the structure in domains such as coordination of care, survivorship and end-of-life care, and operations management. These domains are evaluated in 3 core metrics: return on investment, clinical outcomes, and patient experience.[5] In addition, a complementary navigation metrics toolkit has also been developed by AONN+ focusing on the implementation, measuring, and challenges associated with the AONN+ metrics.[6]

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NSCLC Best Practices

To achieve optimal patient-centered care for individuals with non–small cell lung cancer (NSCLC), numerous reliable resources are available to guide best practices. These range from individual peer-reviewed articles to comprehensive initiatives disseminated by prominent cancer care organizations, including the Academy of Oncology Nurse & Patient Navigators (AONN+), the Association of Community Cancer Centers, the Oncology Nursing Society, and the National Comprehensive Cancer Network. Given the breadth of these resources, integrating them into the creation of a targeted NSCLC navigation program can feel daunting. To streamline this process, standardized navigation metrics can aid in program planning, development, and outcome measurement, all while aligning with NSCLC best practices. The AONN+ Standardized Evidence-Based Metrics framework and the 2020 AONN+/ACS Navigation Metrics Toolkit offers valuable guidance for developing such a navigation program.[1] **Table 1** outlines 10 standardized, evidence-based metrics, along with suggested applications for enhancing NSCLC care.[2,3]

Table 1: Select AONN+ Metrics and Their Applications Toward Best Practices

Domain	Metric and Definition	Criteria	NSCLC Applications Toward Best Practices
Coordination of care and care transitions	Barriers to care: number and list of specific barriers to care identified by navigator per month	CO, ROI	Common barriers to care include patient/caregiver issues, healthcare team issues, healthcare system issues When developing an early-stage NSCLC navigator program, it may be beneficial to initially focus on addressing logistical barriers and examining referral patterns
Coordination or care and care transitions	Diagnosis to initial treatment: number of business days from diagnosis (date pathology resulted) to initial treatment modality (date of first treatment)	PE, CO	Diagnosis in NSCLC would be first the initial signs of NSCLC that trigger additional testing. May be nonspecific
Operations management, organizational development, and healthcare economics	30-, 60-, and 90-day readmission rate	ROI	NSCLC patients often undergo multiple, sometimes simultaneous, treatment modalities, which can raise the risk of hospital admission Providing effective patient education, conducting regular screening, ensuring timely follow-up, and addressing potential barriers may help reduce these admission rates
Psychosocial support services and assessment	Psychosocial distress screening: number of navigated patients per month that received psychosocial distress screening at a pivotal medical visit with a validated tool (NCCN Distress Thermometer)	PE, CO	Since NSCLC patients often see multiple providers, consider implementing the NCCN Distress Thermometer tool across departments to allow for frequent patient assessments. Utilizing the electronic medical record system could facilitate efficient collection and sharing of Distress Thermometer results among the healthcare team

Table 1: Select AONN+ Metrics and Their Applications Toward Best Practices (continued)

Domain	Metric and Definition	Criteria	NSCLC Applications Toward Best Practices
Psychosocial support services and assessment	Social support referrals	PE, CO, ROI	Although various support resources may be available for NSCLC patients, it may be helpful to focus on analyzing 1 service at a time such as social work, mental health counseling, or community support groups. Initially, quality assessment and process improvement efforts can be implemented on a smaller scale to allow for quick, efficient feedback and adjustments
Survivorship and end-of-life care	Palliative care referral: number of navigated patients per month referred for palliative care services	PE, CO, ROI	All NSCLC patients should be referred to palliative care at the earliest opportunity. It may also be useful to track the total number of patients with NSCLC, along with specific data on: • Patients who were referred and initiated palliative care services • Patients who were referred but did not start palliative care, noting whether the decision was deferred by the patient, caregiver, or provider
Patient advocacy and patient empowerment	Identifying learning style preference: number of navigated patients per month whose preferred learning style was discussed during the intake process	PE, CO	If a valid, established tool is unavailable, consider incorporating the following preferences on an intake form or during the initial interview: • Visual (spatial): preference for learning through pictures, images, and spatial understanding • Aural (auditory-musical): preference for learning through sound or music • Verbal (linguistic): preference for using words, both spoken and written • Physical (kinesthetic): preference for hands-on learning and using the body, hands, and touch • Logical (mathematical): preference for logic, reasoning, and structured systems • Social (interpersonal): preference for learning in groups or collaborative settings • Solitary (intrapersonal): preference for working independently and engaging in self-study

Table continues on pg 56.

Table 1: Select AONN+ Metrics and Their Applications Toward Best Practices (continued)

Domain	Metric and Definition	Criteria	NSCLC Applications Toward Best Practices
Professional roles and responsibilities	Navigation knowledge at time of orientation: percentage of new hires that have completed institutionally developed navigator core competencies	CO	After the program development phase is largely complete, the newly appointed NSCLC nurse or patient navigator should undergo a practical competency assessment conducted by an experienced ONN or physician champion to ensure they are prepared to begin practice as novice NSCLC navigators Additionally, mentors should be identified to support their ongoing development toward becoming expert NSCLC ONNs
Research, quality, and performance improvement	Patient experience and patient satisfaction with care: patient experience or patient satisfaction survey results per month using an institutional-specific navigation tool with internal benchmark	PE	Consider implementing a brief patient satisfaction survey aligned with the specific goals of the program. Additionally, organizing focus groups with patients diagnosed with NSCLC and their families may provide valuable feedback after enough cases have been enrolled in the navigation program

CO, clinical outcome; NSCLC, non–small cell lung cancer; ONN, oncology nurse navigator; PE, patient experience; ROI, return on investment.

Standardized Screening and Treatment Guidelines

When screening, treating, and providing care for NSCLC patients, a set of regularly updated standardized guidelines exists that lay out best practices. Guidelines exist for all aspects of care including diagnostics, screening, treatment, and even palliative or end-of-life care. Listed below are some of the resources that may be beneficial to oncology nurse and patient navigators providing care to patients.

Screening

- **United States Preventative Task Force Lung Cancer Screening Guidelines:** www.uspreventiveservicestaskforce.org/home/getfilebytoken/WN7F3WW6RQFDkHay87a3Dx
- **American Cancer Society Lung Cancer Screening Guidelines:** www.cancer.org/health-care-professionals/american-cancer-society-prevention-early-detection-guidelines/lung-cancer-screening-guidelines.html
- **Centers for Medicare & Medicaid Services:** Screening for Lung Cancer with Low Dose Computed Tomography (LDCT): www.cms.gov/medicare-coverage-database/view/ncacal-decision-memo.aspx?proposed=N&NCAId=304&bc=AAAAAAAAAgAAAA

Treatment

- **National Cancer Comprehensive Network Non-Small Cell Lung Cancer Treatment Guidelines:** www.nccn.org/professionals/physician_gls/pdf/nscl.pdf

Supportive care

- **National Cancer Comprehensive Network Palliative Care Guidelines:** https://www.nccn.org/guidelines/guidelines-detail?category=3&id=1454

- **National Cancer Comprehensive Network Distress Management Guidelines:** https://www.nccn.org/guidelines/guidelines-detail?category=3&id=1431

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Resources for NSCLC

For Patients

General Information

CancerCare
www.cancercare.org

Lung Cancer Research Foundation
www.LCRF.org

National Comprehensive Cancer Network (NCCN), Guidelines for Patients
www.nccn.org/patients/guidelines/cancers.aspx

Smoking Cessation

American Cancer Society: Lung Cancer
www.cancer.org/cancer/types/lung-cancer.html

American Lung Association: Smoking Cessation
www.lung.org/quit-smoking

Centers for Disease Control (CDC): Smoking Cessation
www.cdc.gov/tobacco/campaign/tips/quit-smoking/index.html

National Cancer Institute (NCI): Smoking Cessation
https://cancercontrol.cancer.gov/brp/tcrb/smoking-cessation

Smokefree.gov
https://smokefree.gov/

Advocacy and Support Groups

ALK Positive
www.alkpositive.org/

American Lung Association: Advocating for Lung Cancer Patients
www.lung.org/lung-health-diseases/lung-disease-lookup/lung-cancer/get-involved/advocating-for-lung-cancer-patients

Cancer Support Community
www.cancersupportcommunity.org/non-small-cell-lung-cancer

Caring Ambassadors
https://lungcancercap.org/

EGFResisters
https://egfrcancer.org/

Go2 for Lung Cancer
https://go2.org/

KRAS Kickers
KRASKickers.org

LiveLung (Dusty Joy Foundation)
www.dustyjoy.org/

Lung Cancer Alliance
www.lungcanceralliance.org/

LUNGCan
www.lungcan.org/

LUNGevity Foundation
www.lungevity.org/

MET Crusaders
https://metcrusaders.org/

Palliative and End-of-Life Care

Center to Advance Palliative Care
www.capc.org

Get Palliative Care
https://getpalliativecare.org/resources/

Hospice Foundation of America (HFA)
https://hospicefoundation.org

National Comprehensive Cancer Network (NCCN). Clinical Practice Guidelines in Oncology. Palliative Care
www.nccn.org/professionals/physician_gls/pdf/palliative.pdf

National Hospice and Palliative Care Organization
www.nhpco.org/

National Institute of Aging: Providing Care and Comfort at the End of Life
www.nia.nih.gov/health/end-life/providing-care-and-comfort-end-life

Oncology Nursing Society (ONS): Position Statement on Palliative Care for People With Cancer
www.ons.org/make-difference/ons-center-advocacy-and-health-policy/position-statements/palliative-care-people

Palliative Care Network
www.palliativecarenetwork.com

Clinical Trials

American Cancer Society (ACS): Barriers to Patient Enrollment in Therapeutic Clinical Trials for Cancer
www.fightcancer.org/policy-resources/clinical-trial-barriers

American Cancer Society (ACS): The Basics of Clinical Trials
www.cancer.org/treatment/treatments-and-side-effects/clinical-trials/what-you-need-to-know/clinical-trialbasics.html

American Society of Clinical Oncology (ASCO): Cancer.Net: About Clinical Trials
www.cancer.net/research-and-advocacy/clinical-trials/about-clinical-trials

American Society of Clinical Oncology (ASCO): Insurance Coverage of Clinical Trials
www.asco.org/research-progress/clinical-trials/insurance-coverage-clinical-trials

National Cancer Institute (NCI): Clinical Trials Information for Patients and Caregivers
www.cancer.gov/about-cancer/treatment/clinical-trials

National Cancer Institute (NCI): Find NCI-Supported Trials
www.cancer.gov/about-cancer/treatment/clinical-trials/search

National Institutes of Health (NIH): Clinical Trials Database
https://clinicaltrials.gov

National Institutes of Health (NIH): Talking to Your Patient About a Clinical Trial
www.nih.gov/health-information/nih-clinical-research-trials-you/talking-your-patient-about-clinical-trial

Caregiver Support

American Cancer Society (ACS): Caregiver Resource Guide
www.cancer.org/treatment/caregivers/caregiver-resource-guide.html

CancerCare Lung Cancer Caregiver Support Group
www.cancercare.org/support_groups/36-lung_cancer_caregiver_support_group

Caregiver Action Network: Caregiver Help Desk (1-855-227-3640): Community Care Corps
https://caregiveraction.org

Family Caregiver Alliance (FCA) 1-800-445-8106
www.caregiver.org

For Navigators

Professional Development

Academy of Oncology Nurse & Patient Navigators (AONN+)
www.aonnonline.org

The Alliance of Professional Health Advocates (APHA)
https://aphadvocates.org

Association of Community Cancer Centers (ACCC)
www.accc-cancer.org

Association of Oncology Social Work (AOSW)
www.aosw.org

Oncology Nursing Society (ONS)
www.ons.org

Professional Oncology Navigation Task Force Standards of Professional Practice
www.ons.org/sites/default/files/2023-06/Patient%20Navigation%20Standards%20_%20WebViewer.pdf

Glossary

ablation: the medical removal or destruction of tissue, often used to treat cancer or other conditions, through techniques such as heat, cold, or laser

adjuvant: a treatment given after the primary therapy to reduce the risk of recurrence

advance directive: a legal document in which a patient outlines their preferences for medical care and treatments, including end-of-life decisions, in the event they are unable to communicate their wishes

antibody-drug conjugate: a precision cancer therapy that links a monoclonal antibody to a cytotoxic drug

biomarker: a measurable biological indicator, such as a gene, protein, or metabolite, used to assess disease risk, diagnose conditions, monitor progression, or evaluate treatment response

carcinogenesis: the process by which normal cells begin to transform into cancer cells

chemotherapy: a type of cancer treatment that involves the use of drugs to destroy cancer cells or prevent them from dividing and growing

circulating tumor DNA (ctDNA): small fragments of DNA shed by cancer cells into the bloodstream, which can be identified and studied through a liquid biopsy

clinical trial: a research study involving human participants that investigates the safety and effectiveness of new treatments or preventive strategies, often compared with the current standard of care

computed tomography (CT) scan: an imaging procedure that uses X-rays and computer processing to generate cross-sectional images of internal organs

distress: a broad term for any negative emotional, physical, social, or spiritual experience that disrupts a person's ability to manage cancer and its treatments

fine needle aspiration: a minimally invasive procedure that uses a thin needle to withdraw fluid, cells, or tissue from a suspicious area for diagnostic purposes under a microscope

healthcare power of attorney: a legal document that designates a person to make medical decisions on behalf of a patient if they become incapacitated and unable to make decisions for themselves

hemoptysis: the act of coughing up blood or blood-tinged mucus

immune checkpoint inhibitor (ICI): a type of immunotherapy that blocks checkpoint proteins, allowing the immune system to recognize and attack cancer cells more effectively

immunotherapy: a treatment utilizing substances made by the body or in a lab that enhances the body's own immune system to identify and combat cancer

magnetic resonance imaging (MRI): a diagnostic tool that uses magnetic fields to create high-resolution images of the body and assess tumor size

mediastinoscopy: a surgical procedure that allows doctors to examine the space between the lungs, including nearby lymph nodes, for diagnostic evaluation

monoclonal antibodies: laboratory-engineered antibodies designed to target specific antigens on cells, often used as a form of immunotherapy to treat cancer

multidisciplinary: a collaborative approach to care that involves specialists from different healthcare fields working together to develop and deliver a comprehensive treatment plan

neoadjuvant: treatment given before the primary therapy to shrink a tumor and improve the effectiveness of subsequent surgery or other interventions

next-generation sequencing (NGS): a high-speed genetic testing method used to decode the DNA or RNA sequences, helping to inform personalized cancer treatment strategies

oncologist: a doctor who specializes in treating cancer. There are 3 main types: medical oncologists, surgical oncologists, and radiation oncologists

palliative: describes treatments aimed at easing symptoms and improving comfort rather than curing the disease

pathologist: a medical specialist who examines tissue samples under a microscope to determine the presence and characteristics of disease, such as cancer

positron emission tomography (PET) scan: often paired with a CT scan, this imaging test uses a radioactive tracer to highlight active areas of disease within the body

progression: refers to the advancement of cancer, including its growth and potential spread to other parts of the body

psychosocial issues: emotional, psychological, and social challenges associated with cancer and its treatment that may impact overall well-being

quality of life: a measure of an individual's general well-being, comfort, and satisfaction with daily living

resistance: the ability of cancer cells to evade or withstand the effects of treatment, leading to reduced treatment effectiveness

smoking cessation: the process and support measures involved in permanently quitting tobacco use

thoracentesis: a procedure performed to remove excess fluid from the pleural space surrounding the lungs

tumor board: a collaborative meeting where a team of healthcare professionals from various specialties discusses complex cancer cases to develop integrated treatment recommendations

Notes

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