NATIONAL
HEALTH COUNCIL

Patient Experience Dossier

METASTATIC NON-SMALL CELL LUNG CANCER

2026

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Executive Summary

About This Dossier

This Patient Experience Dossier was developed to ensure that the lived experiences, priorities, and unmet needs of people living with metastatic non–small cell lung cancer (mNSCLC), and their caregivers, are meaningfully reflected in decisions that affect them.

This dossier aims to help readers understand the experiences of patients with mNSCLC across the health care continuum. It includes evidence on symptoms, diagnosis, treatment, and management, drawing from scientific research and diverse literature sources.

Intended Audience

PATIENTS

To help newly diagnosed individuals or those living with mNSCLC better understand their condition and make informed health care decisions.

PATIENT ORGANIZATIONS

To provide a resource that is both educational for patients and useful for advancing organization policy

PROVIDERS

To support deeper, more informed discussions with patients about how mNSCLC affects their lives.

PAYERS

To identify areas of financial burden and explore where enhanced coverage could reduce costs and improve outcomes.

INDUSTRY

To highlight gaps in care and opportunities for innovation in screening, diagnosis, and treatment.

HEALTH ADMINISTRATORS

To identify gaps in patient needs and current practices that may provide areas of improvement for health care access processes.

RESEARCHERS

To explore unmet patient needs that can then inform improvement in access to care from a clinical or financial perspective.

This dossier is not clinical practice guidance. Where mNSCLC-specific data were limited, broader NSCLC evidence is cited and clearly noted as proxy evidence.

External Resources can be found on page 21 and a Glossary starting on page 22.

Lung and bronchus cancer is the deadliest form of cancer in the United States, with an estimated 182,730 deaths expected in 2026 (Siegel, 2026).

Most cases are non-small cell lung cancer (NSCLC), which usually starts in one part of the lung. In its most advanced stage (Stage IV), the cancer spreads beyond the lung and becomes metastatic non-small cell lung cancer (mNSCLC) (Zappa, 2016). For this Dossier, please note that data on NSCLC are used as reference where data on mNSCLC is not available.

Patient Clinical Journey & Access to Care

Many people with mNSCLC experience long and difficult paths to diagnosis. Early symptoms—such as cough, fatigue, or shortness of breath—are often vague and commonly treated as minor respiratory illnesses. Patients may visit primary care or urgent care multiple times before lung cancer is considered, and diagnosis often occurs only after symptoms worsen or imaging is finally ordered. As a result, many patients are diagnosed at a late stage, when treatment options are more limited.

Patients with mNSCLC often receive their diagnosis through varied pathways, including primary care, emergency care, or diagnostic procedures for other health issues. These pathways lead to very different timelines and experiences. Delays are often caused by misinterpretation of symptoms, repeated treatment for other conditions, and slow referral to specialists. Some patients receive diagnoses only when symptoms become severe.

Lung cancer screening could support earlier detection, but participation among people who qualify remains low. Barriers include lack of awareness, fear of stigma related to smoking, required shared decision-making visits, and confusion about insurance coverage and costs.

Access to timely diagnosis is further shaped by where patients live, their insurance coverage, and social and economic factors. Rural patients often face longer travel distances and fewer specialists, while insurance denials and unclear coverage can delay testing and increase financial stress.

Holistic Burden of Disease & Impacts on Daily Life

Living with mNSCLC affects nearly every part of a patient's life. After diagnosis, patients face ongoing physical symptoms, emotional distress, and practical challenges while also managing complex treatments. It is often difficult for patients and providers to separate symptoms caused by the cancer from side effects of treatment, which can make symptom management and decision-making more challenging.

Emotional and mental health impacts are common. Many patients experience anxiety, depression, emotional exhaustion, and strain on relationships, particularly around the time of diagnosis and treatment initiation. These challenges can affect daily functioning, treatment adherence, and overall well-being, yet mental health needs are often not fully addressed as part of routine care.

Patients also experience a high symptom burden that affects quality of life. Fatigue, shortness of breath, pain, cough, dizziness, and cognitive difficulties are common and can significantly interfere with daily activities, including walking, sleeping, performing household tasks, and engaging in social activities. As disease progresses, physical functioning often declines, increasing dependence on caregivers.

Daily activities such as cooking, cleaning, shopping, driving, and personal hygiene can become difficult or impossible for many patients. Muscle weakness, frailty, and, in some cases, brain metastases further limit independence and increase the need for assistance.

The financial impact of mNSCLC is severe. Many patients experience lost income, high out-of-pocket costs, and difficulty maintaining employment or insurance coverage. Financial strain increases over time and can contribute to treatment non-adherence and worsening mental health. The time required for frequent appointments, travel, and care coordination adds additional burden and stress.

Caregivers play a critical role in supporting patients but often face substantial time and employment impacts themselves. Caregiving responsibilities commonly include emotional support, daily living assistance, and care coordination, with many caregivers reducing work hours or leaving the workforce altogether.

Patient Perspectives on Current and Future

While treatments are becoming more personalized through genetic and biomarker testing, patients report that awareness, access, and use of these approaches remain inconsistent. Many patients are unsure whether they have received biomarker testing or how test results affect their treatment options.

When considering treatment options, patients value living longer, but they also place strong importance on maintaining daily functioning, preserving independence, and minimizing side effects and hospitalizations. Patients and clinicians may not always prioritize the same outcomes, particularly when it comes to quality of life, side effects, and how treatment information is communicated. Clear explanations and shared decision-making are important to help patients feel informed and supported.

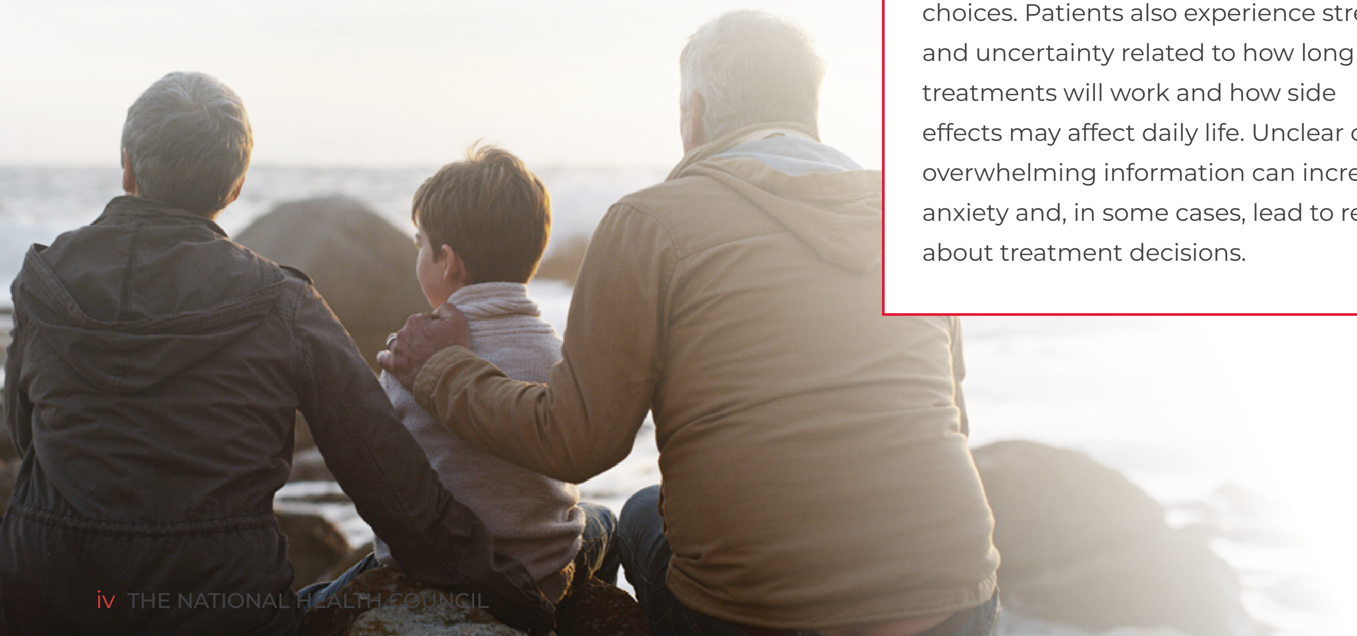
Patients recognize that treatment pathways depend on disease characteristics, test results, and overall health. However, gaps in provider awareness, limited access to targeted therapies, and uneven use of biomarker testing can affect whether patients receive personalized treatment.

Patients also highlight the importance of supportive care, including early palliative care and smoking cessation support when appropriate, as part of comprehensive treatment.

Treatment tradeoffs are a central part of the patient experience. Many patients are willing to accept more side effects if it means a meaningful increase in survival, especially earlier in the disease course or for the chance of long-term benefit. Others place greater value on comfort, symptom control, and quality of life. Preferences vary by age, disease progression, and the presence of brain metastases.

SIDE EFFECTS

Side effects, such as fatigue, shortness of breath, bleeding, nausea, and skin problems, strongly influence treatment choices. Patients also experience stress and uncertainty related to how long treatments will work and how side effects may affect daily life. Unclear or overwhelming information can increase anxiety and, in some cases, lead to regret about treatment decisions.



Unmet Patient Needs

People living with mNSCLC face many unmet needs that go beyond medical treatment. Patients and caregivers describe ongoing challenges related to emotional well-being, financial stress, access to clear and understandable information, care coordination, and social support.

Many patients report gaps in understanding their treatment options, prognosis, and potential side effects, particularly for newer or targeted therapies. Patients often want more realistic and timely information about what to expect over the course of their disease. Limited awareness of biomarker testing, clinical trials, and emerging treatments further contributes to uncertainty and missed opportunities for care.

Emotional and mental health needs are frequently underaddressed.

Patients commonly experience anxiety, depression, stigma, and feelings of isolation, while access to counseling, peer support, and lung cancer–specific support groups remains limited. Financial strain is widespread and often worsens over time, especially when patients or caregivers reduce work hours or lose employment.

Care coordination is another major challenge. Patients and caregivers often struggle with scheduling appointments, navigating complex health care systems, and accessing supportive and palliative care services. Many patients report delayed or limited access to palliative care due to misunderstandings about its role, even though these services can improve quality of life.

Patients also highlight gaps in how outcomes are measured. Many symptoms and impacts on daily life that matter most to patients are not fully captured by existing patientreported outcome tools. Improving education, communication, shared decision-making, navigation services, and efforts to reduce stigma could help address these unmet needs

Patient Clinical Journey & Access to Care

SECTION HIGHLIGHTS

1. Many patients first present with **nonspecific symptoms** managed as benign conditions, delaying referral and definitive imaging.
2. **Late-stage diagnosis is common;** a minority of NSCLC cases are found at localized stage in population data.
3. Screening for high-risk individuals remains underused due to **knowledge gaps, stigma, and insurance/process hurdles.**
4. **Access to specialists, navigation, trust-building communication, and coverage clarity** strongly influence time to treatment, especially for rural and

Patient Diagnosis Experiences

A patient's journey to diagnosis for mNSCLC significantly influences their likelihood of survival and other favorable outcomes. Health care providers (HCPs) often attribute early symptoms for other conditions like pneumonia and other respiratory infections. Patients often repeat these initial visits with their primary care provider before receiving the correct diagnosis and treatment with a specialist. First steps to diagnosis include a chest x-ray and/or chest CT scan. Vague symptoms or repeated delayed diagnostic tests often lead to patients not seeking specialty care until the disease is at a late stage. Annual rates of screening for high-risk individuals are low, which may be due to HCP unfamiliarity, and patient's concerns regarding smoking stigma and judgement. Confusion around how and when insurers cover these tests may hinder uptake of screenings as well. Financial strains due to coverage in general around diagnostic tests for mNSCLC persists, with access disparities being especially pronounced for rural populations. Based on the most current data, this section provides a deeper understanding of the patient's clinical journey from diagnosis to access to care.

Diagnosis & Survival

Survival in mNSCLC is strongly influenced by how early the disease is detected. Delays in diagnosis—often occurring during the primary care phase—can have devastating effects, as most cases are not identified until the cancer has already advanced. In fact, only 16% of NSCLC cases are diagnosed at a localized stage, while approximately 40% present at Stage IV, or metastatic, when treatment options are more limited and outcomes are poor (Cancer Facts & Figures 2018; McMullen et al., 2019).

In 2024, an estimated **234,580 people** in the United States were diagnosed with lung and bronchus cancer, and **125,070 died from the disease** (Siegel et al., 2024). This highlights the critical importance of timely recognition and intervention in improving survival outcomes.

The path to diagnosis varies widely depending on symptom presentation, patient help-seeking behavior, and health care provider recognition and response (Rankin et al., 2017).

Types of Pathways to Diagnosis & Treatment

Patients may receive a mNSCLC diagnosis through various pathways such as primary care, emergency care, or diagnostic procedures for other health reasons. Symptoms often persist beyond initial treatment attempts, signaling the need for further evaluation.

DIAGNOSIS & SYMPTOMS

A large survey of **22,799 patients with Stage IV NSCLC** diagnosed between 2007 and 2018 found that nearly all **(94.4%)** experienced at least one moderate-to-severe symptom—most commonly tiredness, feeling unwell, poor appetite, and shortness of breath.

> **Eventually, worsening or changing symptoms—such as increased cough, fatigue, or shortness of breath— prompted patients to re-engage with health care providers, often leading to further diagnostic evaluation.**

These symptoms tended to peak around the time of diagnosis and, although they often improved over the following year, many persisted (Tjong et al., 2021).

Despite these symptoms, patients often had a low perception of risk, initially attributing them to benign causes such as infections or aging.

This misattribution frequently led to delays in seeking care or repeated visits for presumed minor illnesses.

Types of Pathways to Diagnosis & Treatment

HEALTH SYSTEM

Physicians often initially treated patients for other respiratory or common illnesses, such as pneumonia or bronchitis, before considering lung cancer as a possible diagnosis.

In many cases, an abnormal finding on imaging—typically a chest X-ray (CXR) or chest CT scan—was the key factor leading to further investigation and eventual diagnosis.

For some patients, the severity or sudden worsening of symptoms (e.g., severe shortness of breath, chest pain, or hemoptysis) prompted emergency evaluation, expediting diagnostic **testing and referral to specialists.**

Figure 1 demonstrates the multiple and complex pathways to obtaining an mNSCLC diagnosis and treatment. Patients may experience different variations leading to differences in care.

Figure 1. Multiple Patient Pathways (Adapted from Al Achkar et al., 2021)

Types of Pathways to Diagnosis & Treatment

DELAYED DIAGNOSIS DUE TO SYMPTOM MISRECOGNITION

Many patients experience delayed diagnosis because early lung cancer symptoms are vague and often attributed to less serious causes. Common early symptoms—such as a persistent cough, fatigue, chest or musculoskeletal pain, or unexplained weight loss—may be misinterpreted as signs of infection or aging. As a result, patients frequently undergo repeated visits to primary care before lung cancer is considered. Although some cases are discovered incidentally on imaging for unrelated issues, these are typically diagnosed at more advanced stages.

> **Diagnostic focus on other illnesses:** Delays can occur when health care providers pursue alternative explanations for symptoms, excluding lung cancer from the differential diagnosis. These decisions are shaped by early patient–provider interactions and initial symptom interpretation (Carter-Harris et al., 2015; Rankin et al., 2017).

> **Incomplete smoking history disclosure:** Delays may also arise when patients do not share, or clinicians do not inquire about, smoking history—an important risk factor that could prompt earlier investigation.

> **Patient-reported experiences:** Patients often describe their cough as “lingering,” “persistent,” or “bad,” and may also report fatigue, weight loss, or chest pain (Carter-Harris et al., 2015; Rankin et al., 2017).

> **Recognition after repeated visits:** Qualitative studies show that many patients recall a pivotal turning point when their health care provider began to take their concerns seriously—often after multiple consultations or failed antibiotic treatments (Rankin et al., 2017).

> **Referral delays:** Repeated primary care visits without timely specialist referral can significantly prolong diagnosis and worsen care experiences (Mendonca et al., 2016; Rankin et al., 2017).

DELAYED HELP-SEEKING BY PATIENTS

Some patients remain asymptomatic in the early stages, while others minimize or misattribute symptoms—for example, assuming a cough or fatigue is due to a minor illness or smoking.

Over time, as symptoms intensify or persist, patients are more likely to seek medical evaluation (CarterHarris et al., 2015).

ACUTE SYMPTOM PRESENTATION

Patients presenting with sudden or alarming symptoms, such as hemoptysis, severe pain, or respiratory distress, typically undergo immediate diagnostic evaluation, leading to faster identification and initiation of treatment (Carter-Harris et al., 2015).

INCIDENTAL DIAGNOSIS

Lung cancer may also be discovered incidentally during evaluations for unrelated issues, such as a preoperative chest X-ray (Carter-Harris et al., 2015). Because Stage I disease is rarely detectable via plain radiograph, these incidental findings often occur at more advanced stages of disease.

Lung Cancer Screening & Barriers

Screening for lung cancer is a key opportunity for early detection; however, participation among high-risk populations remains low. Barriers include limited provider awareness of updated guidelines, patient stigma associated with smoking, and logistical obstacles in navigating coverage and access. Strengthening education for HCPs and improving patient communication about screening and clinical trials can help enhance uptake and outcomes.

UNFAMILIARITY WITH SCREENING GUIDELINES

Many providers are unfamiliar with current lung cancer screening (LCS) criteria, and patients are often unaware that they qualify for annual screening (Reihani, 2021; Wang et al., 2019).

The U.S. Preventive Services Task Force (USPSTF) recommends annual Low-Dose Computed Tomography (LDCT) screening for current and former smokers who meet specific age and smoking history criteria. However, adherence remains extremely low, with only 16% of high-risk adults being screened nationally (State of Lung Cancer 2024 Report, 2024).

Some experts note that current guidelines may exclude certain high-risk groups and have suggested broadening eligibility and increasing provider education to close persistent screening gaps.

STIGMA AND FEAR OF SCREENING

The beliefs and attitudes of people who smoke can limit LCS use. For example, fear of a cancer diagnosis, as well as perceived stigma and a sense of being blamed for having smoked may lead to avoidance of screening (Al Achkar et al., 2020; Carter-Harris et al., 2017; Hamann et al., 2018).

IMPACT OF COVERAGE ON SCREENING

Although CMS and private insurers cover LCS without cost sharing, confusion about billing codes and coverage details contributes to low participation (Salgia et al., 2021; Wang et al., 2019).

Errors in coding (e.g., diagnostic vs. screening codes) may result in unexpected bills for tests that should have been covered.

The requirement for a shared decision-making (SDM) visit prior to reimbursement adds another logistical barrier. As a result, many individuals are discouraged by perceived financial barriers even when screening is technically available at no cost.

SHARED DECISION-MAKING (SDM) CHALLENGES

Current SDM tools often fail to account for varying health literacy, language needs, and numeracy levels, exacerbating disparities (Rivera et al., 2020a, 2020b).

In addition, research on the potential longterm risks of CT scan screening has sparked an ongoing debate about the possibility of CT-related cancers(Smith-Bindman et al., 2025). Although the American College of Radiology has disputed specific findings from this study, it acknowledges that the risk associated with CT scans is not zero (ACR Statement on JAMA CT Scan Radiation Study (Smith-Bindman, et Al), n.d.).

QUALITY MEASURES

Lung cancer is the only early detectable cancer not included in the Healthcare Effectiveness Data and Information Set (HEDIS) measures. However, the National Committee for Quality Assurance (NCQA) is committed to developing a HEDIS® quality measure for lung cancer screening in 2022, and as of early 2025, it is currently available for public comment ("Public Comments," n.d.; Reynolds, 2022).

TRUST & COMMUNICATION

Patients' distrust can hinder the delivery of preventive care (Rivera et al., 2020a; Wang et al., 2019).

Previous research indicates that even unintentional bias, blame, and nihilism from clinicians can negatively affect interactions with lung cancer patients. Many patients report feeling judged, especially regarding their smoking history, which can erode trust and hinder open communication (Hamann et al., 2018).

Barriers & Facilitators of Access to Care

Barriers to accessing care for an accurate diagnosis and best treatment include a lack of specialists, underutilization of targeted treatments, health insurance denials, stigma against smoking, and transportation to care centers. These problems are more pronounced for rural

- Access to care is shaped by **geography, insurance, socioeconomic status, stigma, and systemic inefficiencies.**
- **Rural patients** face limited access to specialists, imaging, and advanced therapies.
- **Insurance-related** barriers, including denials, appeals, and unclear coverage, add financial strain.
- **Socioeconomic disparities, logistical challenges, and stigma** related to smoking contribute to delayed diagnosis and poorer outcomes.
- **Targeted interventions** are needed to reduce care fragmentation and improve access to equitable treatment across populations.

GEOGRAPHIC CHALLENGES

Patients living in rural or remote regions often encounter limited access to specialists, imaging centers, and targeted therapies. These geographic disparities contribute to delayed diagnosis, suboptimal treatment, and higher mortality rates.

- Patients living far from major cancer centers, particularly in rural settings, **struggle to find local doctors with expertise** in targeted therapies and to thoracic surgeons(Al Achkar et al., 2020; Eberth et al., 2019).
- **Regional variations in access, resources, and cultural factors** lead to end-of-life care disparities (Chen et al., 2020).

Addressing these challenges requires ensuring that local clinicians are trained in appropriate screening practices and have access to necessary care facilities.

HEALTH INSURANCE CHALLENGES

Health insurance plays a major role in determining access to diagnostic testing and treatment. Denied claims, lengthy appeals processes, and uncertainty about coverage for newer therapies can limit care options and delay treatment initiation.

- **Denied claims, appeals processes, and uncertainty** regarding prognosis hamper financial planning (Al Achkar et al., 2020).

SOCIOECONOMIC FACTORS

Socioeconomic and cultural factors significantly influence patients' ability to access, adhere to, and benefit from care.

Financial, educational, and cultural disparities influence access and care experiences (Islam, Deviany, et al., 2019).

Community-level stigma, lack of caregiver support, and logistical barriers—such as transportation—further impede access to specialists and ongoing treatment.

Holistic Burden of Disease & Impacts on Daily Life

SECTION HIGHLIGHTS

1. Living with metastatic non-small cell lung cancer (mNSCLC) affects all aspects of patients' **physical, emotional, and social functioning.**
2. **High symptom burden, including fatigue, pain, and cognitive changes,** impairs daily life and quality of life (QoL).
3. Mental health effects such as **depression, anxiety, and emotional exhaustion** are common and often underaddressed.
4. **Financial and caregiving burdens** add to the overall strain, contributing to distress and treatment nonadherence.
5. **Supportive care, early palliative involvement, and psychosocial support** are essential to mitigating holistic burden.

Patient Experiences After Diagnosis

Living with mNSCLC affects every aspect of a patient's life, imposing both emotional and physical burdens on daily tasks, alongside the challenges of managing the disease itself. Treatment outcomes can range from cures to chronic disease management, to worsening of the condition and symptoms. Addressing these concerns is hindered by the complexity of detangling condition symptoms from treatment side effects. Patient and caregiver burden often increases due to more aid, while many caregivers cut work hours. Financial and economic impacts are severe in this population, with job losses and early retirement common. More than a quarter of patients during first treatments and over half of patients on subsequent treatments report financial strain. This can worsen adherence to treatments and cause a rise in depression symptoms. Disparities exist in health care costs and end-of-life care utilization for all racial and ethnic groups relative to Non-Hispanic White patients.

Emotional & Psychosocial Impacts

Mental health concerns are pervasive and often insufficiently managed in the mNSCLC population. Emotional exhaustion, anxiety, and depression correlate with poorer treatment adherence and outcomes.

Patients with NSCLC often experience **severe depressive symptoms**, especially around diagnosis/treatment initiation, which may affect disease course (Andersen et al., 2020).

Patients often struggle with **walking, sleeping, and performing daily activities,** alongside emotional challenges such as anxiety, depression, and strained relationships (Cardellino et al., 2023).

Over one-quarter of patients report **"catastrophic" effects** on emotional well-being (Tufman et al., 2022).

Symptom Burden & Quality of Life

General symptoms for advanced or metastatic NSCLC include fatigue, cough, pain, dizziness, cognitive issues, and headaches. As with other cancers, symptoms from the condition increase in stages III – IV.

- Common symptoms include **fatigue, dyspnea (shortness of breath), cough, pain, dizziness, and cognitive changes**(Cardellino et al., 2023; Cella et al., 2023; Iyer et al., 2013; Larsson et al., 2012; McMullen et al., 2019). These symptoms impact physical and psychological functioning, relationships, and daily activities such as walking and household tasks (Cardellino et al., 2023).
- **Difficulty distinguishing disease symptoms from treatment side effects** complicates management (Cardellino et al., 2023).
- Stages III/IV NSCLC are strongly linked to **impaired physical functioning and diminished QoL** (Bade et al., 2021).

Activities of Daily Living (ADL)

Patients with mNSCLC struggle with activities of daily living due to symptoms and side effects from treatments. Tasks patients can struggle with include cooking, cleaning, grocery shopping, general mobility, driving, and

- Patients report **difficulty performing household tasks, grocery shopping, or maintaining hygiene due to fatigue and pain**(Cardellino et al., 2023). Muscle weakness and frailty exacerbate mobility challenges and dependence on caregivers (Cardellino et al., 2023). Patients with brain metastases often require help with driving, recreation, self-care (bathing, walking) (Cella et al., 2023).
- **Pre-frail and frail mNSCLC patients experience greater pain and functional impairments than non-frail patients.** This highlights the need for early preventive interventions addressing social, functional, and pain-related challenges (Gabbard et al., 2024).

Economic Impacts on Patients

The economic impact on patients with general NSCLC is immense. There can be high out-of-pocket costs and repeated outpatient visits. Nearly a quarter of mNSCLC patients experience severe financial impacts. These issues can lead to non-adherence and mental health strains.

FINANCIAL TOXICITY

- Nearly one in four Stage IV patients report **severe financial impact.** Lost income, difficulty planning finances, and early retirement are common in Stage IV NSCLC (Tufman et al., 2022).

> Another concern in the United States is the loss of insurance coverage following job loss (Yabroff et al., 2024).

- Severity of financial hardships increases as disease progresses; **27% of patients on first-line treatment and 56% on subsequent lines report financial strain** (Roy et al., 2023).
- **High out-of-pocket costs can lead to treatment non-adherence and worse outcomes.** It can negatively affect patients' QoL, psychological well-being, and survival. Interventions such as financial assistance are critical (Bello & Makani, 2023).

HEALTH CARE COST & UTILIZATION

- NSCLC is associated with substantial health care utilization, particularly outpatient visits (Zhang et al., 2022).
- Disparities in hospital inpatient costs, laboratory costs, and end-of-life care utilization among patients with NSCLC were higher for all racial/ethnic groups relative to Non-Hispanic White patients (Chen et al., 2020).

TIME TOXICITY

The time burden of frequent appointments, travel, and treatment regimens further adds to patient distress.

> Routine lab tests and check-ins could be streamlined or conducted locally to reduce time spent navigating the health care system.

Caregiver Burden

The high symptom load and treatment complexity for mNSCLC patients result in substantial caregiver responsibility. For patients with NSCLC, caregiving hours can average nearly 30 hours a week, often with reduction in paid work hours.

SCOPE OF CAREGIVING DUTIES

Caregivers assist with a range of tasks, including emotional encouragement, meal preparation, shopping, medication management, travel assistance, dressing, planning activities, and both medical and non-medical responsibilities (King-Kallimanis et al., 2024; Wood et al., 2019).

TIME COMMITMENT & EMPLOYMENT IMPACT

- On average, caregivers devote 29.5 hours per week to supporting patients in Europe (Wood et al., 2019).
- Caregivers often make employment changes due to caregiving demands: In a LUNGevity survey, 22% of caregivers cut work hours in the first year, rising to 31% thereafter (King-Kallimanis et al., 2024).

> The most common change was reduced work hours, affecting 11% of caregivers in the first year and 10% beyond the first year.

Patient Perspectives on Current and Future Treatments

SECTION HIGHLIGHTS

1. **Treatment for mNSCLC is increasingly personalized through biomarker and genetic testing,** yet awareness and implementation remain inconsistent.
2. **Patients value extended survival, maintenance of daily functioning, and minimized treatment burden** when weighing therapy options.
3. **Gaps persist between patient and physician priorities,** particularly around side effects, QoL, and communication.
4. **Emotional, logistical, and financial barriers** influence treatment adherence and satisfaction.
5. Enhanced patient education, shared decision-making, and access to precision medicine **can improve treatment alignment and outcomes.**

Patient Perspectives on Treatments

Common cancer treatments such as surgery, radiation, or chemotherapy are often used as front of line care for mNSCLC, however uptake of effective interventions such as targeted therapies based on genetic or biomarker testing are erratic. Ineffective acceptance of genetic or biomarker testing may be due to lack of HCP awareness, presenting a significant unmet need. HCPs, such as oncologists, and patients may have different views of treatment needs and trade-offs – with most decisions regarding treatment being shared between them. In terms of treatment decision-making, patients' highest considerations were for extended life expectancy, slowing/stopping cancer growth, remission, preserving activities of daily living, and reducing hospitalizations from adverse events. However, treatment trade-off considerations are complex; patients and caregivers may prioritize months of progression-free symptoms to avoid severe side effects but accept more significant side effects for substantial survival gains, especially if they are younger.

Current Treatment Pathways

Treatment strategies for mNSCLC are guided by tumor stage, biomarker profile, and the patient's overall condition. Personalized treatment—based on genetic and biomarker testing—can significantly improve survival outcomes. Increasing health care providers' understanding and use of genetic testing may enhance awareness of individualized treatment options. Comprehensive care for mNSCLC should also incorporate smoking cessation counseling and palliative care.

TYPES OF TREATMENTS

Systemic therapy is common for mNSCLC. Surgery, radiation, or chemotherapy may reduce metastasis-related symptoms (Riely et al., 2024).

NCCN Guidelines recommend determining histologic subtype and actionable biomarkers before therapy (Riely et al., 2024).

- Targeted therapy may be recommended depending on biomarker testing results. However, many types of mNSCLC do not have a known biomarker. In these cases, treatment choice may be determined by a person's physical functioning.
- Retrospective data show that conducting molecular testing before starting treatment is linked to longer overall survival (OS) in patients with advanced nonsquamous NSCLC (Aggarwal et al., 2023).

Early palliative care has been shown to improve patients' QOL (Riely et al., 2024).

- Smoking cessation counseling (if needed) and early palliative care should be part of the treatment plan for metastatic NSCLC.

BIOMARKER & GENETIC TESTING

Comprehensive molecular profiling has become central to mNSCLC management, yet testing rates remain suboptimal.

- Biomarkers are either driver mutations, gene alterations, and/or non-genomic biomarkers that are not related to inheritance within a family. All patients with advanced or metastatic nonsquamous NSCLC (or unspecified NSCLC) should have biomarker testing for EGFR, ALK, KRAS, ROS1, BRAF, NTRK1/2/3, METex14 skipping, RET, and ERBB2 (HER2) alterations (Riely et al., 2024).

> Often, patients are unaware if they have been tested or whether they have an actionable biomarker. 20% of mNSCLC patients tested for biomarkers were unaware of their results (Tufman et al., 2022).

> EGFR testing rates are low overall, even if slightly higher in Stage IV (15%) vs. Stages I–III (8%) (Tufman et al., 2022).

- Recent findings from the LEADER trial indicate that comprehensive genomic tested should also be standard among those with early-stage disease as another way to identify the alterations mentioned above through a more in depth examination of an individual's entire genome (Chaft et al., 2024).
- Stakeholders have raised concerns about insufficient physician training for precision diagnostics (Munksted & Van Liew, 2023).

Treatment Decision-making

Treatment decision-making is complex and differs for each patient, especially due to patient age and clinical status. Therapies may be rejected or withheld due to side effects, poor performance status, disease progression, patient refusal, and comorbidities. Treatment goals differ between patients and providers, so patient preference studies are important.

BALANCING BENEFITS & RISKS

- Patients and physicians consider potential survival gains vs. side effects, cost, and individual clinical status (MacEwan et al., 2020; McMullen et al., 2019).

> Patient preferences may vary based on the number of lines of therapy they have experienced (Janse et al., 2021).

> Chemotherapy side effects that patients most want to avoid include: shortness of breath, bleeding, and fatigue (Islam, Anggondowati, et al., 2019).

- Treatment decisions for NSCLC are typically a shared process, with physicians serving as the primary source of information. However, therapy may be withheld due to factors such as poor performance status, rapid disease progression, patient refusal, and comorbidities (Tabchi et al., 2017).
- Patients may be more willing to trade off expected survival for a chance at “durable,” or long-term, survival (Hauber et al., 2020).
- Discordant goals between patients and oncologists often persist through end-of-life (Douglas et al., 2019; Golden et al., 2022).

Treatment Side Effects

Reported severe side effects include skin problems, nausea, hair loss, infections, infusion reactions, edema, fatigue, weight changes, shortness of breath, and bleeding.

- Common side effects (e.g., severe skin issues, nausea, hair loss, infections, infusion reactions, edema, fatigue, weight changes) heavily influence treatment choices (Petrocchi et al., 2021).
- Among mNSCLC patients undergoing chemotherapy, the top three side effects that patients would most like to avoid are shortness of breath, bleeding, and fatigue (Islam, Anggondowati, et al., 2019).

UNCERTAINTY & STRESS

Patients often experience significant anxiety due to uncertainty about how long treatments will remain effective and the unpredictability of side effects. Providing clear, patient-friendly information can help reduce this stress (Petrocchi et al., 2021).

> Patients with advanced lung cancer may experience feelings of regret regarding their treatment decisions, especially if they notice a perceived decline in their health early in the treatment journey (Hollen et al., 2021).

Meaningful Treatment Benefits

Meaningful treatment benefits include increasing overall survival and reducing hospitalizations due to adverse effects. Patients may tolerate higher side effects for longer-term survival; however, depending on the patient demographics, quality of life may be more important than survival gains. The type of metastases may also affect treatment preferences with brain metastasis patients valuing delaying symptom progression over other types of outcomes.

PATIENT PERSPECTIVES ON TREATMENT VALUE & TRADEOFFS

Patients define meaningful outcomes in ways that extend beyond survival metrics, emphasizing everyday functioning, emotional stability, and independence.

Patients value everyday functioning, emotional stability, and independence. (Petrocchi et al., 2021):

In a study of nearly 500 patients with mNSCLC and their caregivers, the highest priority was extending overall survival from 11 to 30 months, followed by reducing hospitalizations due to serious adverse events (Yong et al., 2022).

Many patients are willing to accept higher risks of side effects for even small chances of long-term survival (5+ years), though others prioritize QoL over survival gains (Oliveri et al., 2023).

Age influences preferences: younger patients tend to value survival duration more than QoL, while older patients often prioritize comfort and daily functioning (Islam, Deviany, et al., 2019).

Delaying symptom progression is particularly meaningful for many. In one study, **75% of patients with brain metastases valued delaying symptoms to maintain QoL**, while others prioritized tumor reduction or life extension due to severe existing symptoms (Cella et al., 2023).

Patients and caregivers are often willing to trade several months of progressionfree survival (PFS) to avoid severe side effects but will tolerate more toxicity for substantial survival benefits (Janssen et al., 2020).

Advances in targeted therapies have led to the hope that lung cancer may be managed long-term as a chronic disease (Al Achkar et al., 2020).

However, lung cancer–related stigma may still discourage some patients from seeking treatment.

Unmet Patient Needs

SECTION HIGHLIGHTS

1. Patients with mNSCLC face numerous unmet needs across **emotional, financial, educational, and logistical domains.**
2. Gaps exist in **treatment awareness, education about prognosis and side effects,** and access to supportive and palliative care.
3. **Emotional distress, financial toxicity, and disease-related stigma** exacerbate challenges in daily living and treatment adherence.
4. **Care coordination and navigation services** are inconsistently available, leaving patients and caregivers to manage fragmented systems.
5. **Strengthening education, patient-centered communication, and community support** can improve patient outcomes and quality of life.

Patient Unmet Treatment Needs

Unmet needs among patients with mNSCLC are extensive and span multiple domains, including financial support, mental and emotional health, access to educational materials, disease-related stigma, care coordination, and precision treatment options.

Patients and caregivers report opportunities to improve health care delivery, including addressing gaps in provider knowledge regarding genetic screening, clinical trial availability, emerging treatment options, realistic expectations for survival and disease progression, palliative care integration, and referrals to mental health services.

At the societal and patient organization level, there is a strong demand for lung cancer–specific support groups, expanded financial assistance programs, and public awareness campaigns aimed at reducing social stigma and discrimination.

Pharmaceutical manufacturers are encouraged to:

- Develop treatment options that extend survival and improve quality of life.
- Provide clearer information about clinical trials.
- Optimize medication design by reducing pill size and the number of daily doses required.

Researchers are urged to prioritize patientreported outcomes and qualitative studies that capture real-world experiences, including symptoms, side effects, and broader patient needs—areas patients consistently identify as lacking in current research.

CLINICAL TRIAL AWARENESS

Limited knowledge of clinical trials and waiting too long to provide information about clinical trials to patients results in patients may no longer being eligible to participate.

In a Survey conducted by LUNGevity (Understanding Barriers to Participation in Clinical Trials: The Patient and Caregiver Perspectives, n.d.):

> **Patients prioritized patient advocacy groups as a source of clinical trial information**

> **Caregivers prioritized the patient's doctor as a preferred source of receiving information about clinical trials**

AWARENESS, OPTIONS, AND GOALS

Desire for Additional, More Effective Treatment Options:
Stage IV patients more often desired additional treatment options (32% vs. 21%) and prioritized extending life (48% vs. 42%) (Tufman et al., 2022).

Different Treatment Priorities by Stage:
Stage IV patients more frequently expressed a need for additional treatment options (32% vs. 21% for Stage I–III) and prioritized life extension as a treatment goal (48% vs. 42%). In contrast, Stage I–III patients were slightly more focused on reducing tumor size (33% vs. 30%) and achieving symptom relief (18% vs. Stage IV).

Unmet Needs in Treatment Delivery:
While over 60% of patients had no issues with oral medications, 40% struggled with pill sizes and shapes, and 20% found managing multiple pills daily challenging, highlighting unmet needs in treatment delivery (Tufman et al., 2022).

Education & Information Needs

Patient unmet needs are not limited to novel treatments and may include increased education and expectations for survival, side effects, and

INFORMATION ABOUT EXPECTED TREATMENT OUTCOMES & SIDE EFFECTS

> Patients on targeted therapies often lack clarity on survival and disease progression expectations (Al Achkar et al., 2020).

> Education about symptoms, side effects, and survivorship is critically needed (Safavi et al., 2024).

> Ideal timing is upon diagnosis and in tandem with receiving their treatment plan and through discussions with their HCP (see shared decision-making).

Emotional, Logistical, and Financial Support

Emotional health and peer support assistance are lacking with many patients facing mental health distress, financial toxicity, stigma, and symptom issues. This could be improved through mental health and cancer support group referrals. Oncologist interactions can be limited to physical clinical support and treatment plan updates rather than holistic health.

1. Patients with NSCLC have significant unmet information needs, particularly related to managing the emotional and financial burdens of their condition (Tufman et al., 2022).
2. People with mNSCLC often require emotional support to cope with their condition and practical help to manage the daily challenges of illness and treatment.
3. Patients with NSCLC often feel stigmatized or dismissed because of their diagnosis (Dy et al., 2017).
4. Over half of patients reported unmet care needs in psychological and physical or daily living areas, while 52% experienced financial hardship in at least two domains. Caregiver employment reduction was significantly associated with greater patient-reported financial hardship and distress (McLouth et al., 2021).

ACCESS TO SUPPORT GROUPS

Patients desire access to support groups, especially those tailored for mNSCLC without a religious focus. Many patients express frustration that cancer centers often fail to connect them with these resources, as oncologist interactions are typically limited to clinical updates and treatment plans (Al Achkar et al., 2020).

> **There are fewer than 100 lung cancer-specific patient support groups across the United States,** which can make it difficult for patients to identify one that is convenient for them. Additionally, many cancer support groups are not specific to lung cancer and, therefore, do not necessarily address the needs of lung cancer patients, who have different challenges, such as stigma, high mortality rates, and targeted therapies.

> More focus should be placed on connecting patients with others who are on a similar journey.

Patient Perspectives on Outcomes & Measurement Tools

Future studies for mNSCLC should include patient-centered studies that fully capture symptoms and other aspects of the condition.

> Further refinement of Patient Rreported Outcome Measurements is needed to ensure they address the full scope of patient experiences.

ALIGNMENT OF PROMS WITH PATIENT-REPORTED SYMPTOMS

A mapping of patient-identified symptoms to common PROMs (EORTC-QLQ-C30, EORTC-QLQ-LC13, NSCLCSAQ) showed gaps in capturing dizziness, skin/nail changes, headache, swelling, wheezing, and functional impacts (e.g., difficulty exercising, lack of motivation, weight changes) (Cardellino et al., 2023).

Care Coordination Support

Coordination of care for this condition can be an important barrier to optimal outcomes. Patients may need assistance with scheduling appointments, psychosocial support, and generally accessing comprehensive cancer care. Palliative care can improve patients QoL but there is often misinformation and undereducation regarding its function.

CHALLENGES IN CARE COORDINATION

Patients often struggle with scheduling appointments and accessing the care they need (Al Achkar et al., 2020).

Early access to supportive, palliative care is critical, and some patients express regret over delayed introduction to these services (Al Achkar et al., 2020).

> There is misinformation and misconception about palliative care in the lung cancer community. Palliative care has been shown to reduce hospital admissions and improve QoL. However, a common misconception is that palliative care is synonymous with hospice (McLouth et al., 2023).

GAPS IN NAVIGATION PROGRAMS

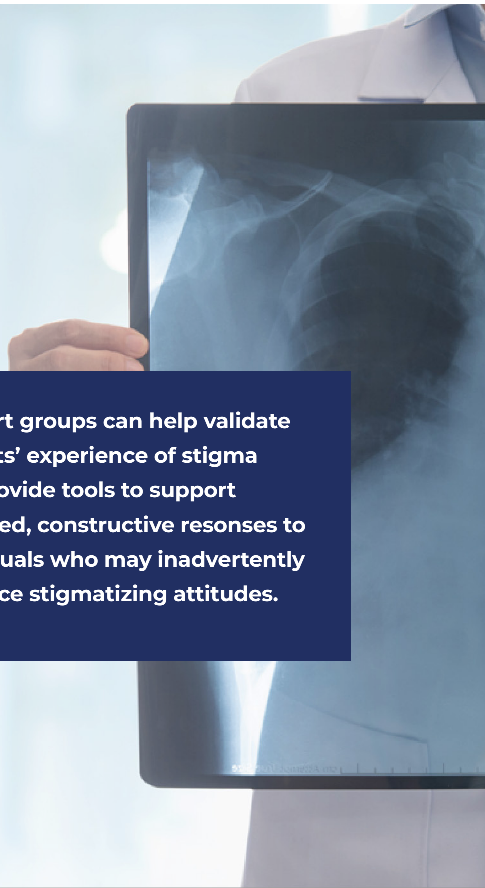
While patient navigation programs are implemented across US communitybased cancer programs, their design and delivery vary, leaving some patients without comprehensive cancer care, including psychosocial support, future planning, and health promotion strategies (Aversano, 2022; Petrillo, 2021).

> Integrating patient navigation with specific treatments is underexplored, and its long-term impact on outcomes remains inconsistently reported (Bush, 2018).

Overcoming Stigma Associated with Lung Cancer

Stigma is a substantial barrier to accurate diagnosis, treatment, population understanding, and individual emotional health for a

- Stigma remains a significant obstacle, negatively affecting psychosocial well-being, communication, diagnosis and treatment access, and research funding (Hamann, 2018).
- Patients feel that lung cancer is unfairly stigmatized due to its association with smoking, despite the fact that not all lung cancer cases are smoking-related (Dy et al., 2017).
- Many patients express a desire for reduced stigma, noting that public assumptions about smoking contribute to feelings of blame and exclusion (Al Achkar et al., 2020).



Support groups can help validate patients' experience of stigma and provide tools to support informed, constructive resonses to individuals who may inadvertently reinforce stigmatizing attitudes.

Opportunities for Improvement

Improvements in educational materials, health-literacy informed communication, and shared decisionmaking tools would be beneficial for patients in this space. Providers can enhance integration of care between PCPs and oncologists as well as address their own gaps in screening eligibility knowledge and use of stigmatizing language.

IMPROVED COMMUNICATION & EDUCATION

Clear, accessible language and educational materials help support patient understanding.

- Adapting conversations to match the patient's level of understanding, offering educational materials, emphasizing key messages through different explanations, and using a call-and-response method to involve patients are effective ways to support shared decision-making (Chihuri, et al., 2024).
- Complex terms such as oligometastatic disease add complexity to shared decision-making (Chihuri, T et al., 2024).

SHARED DECISION-MAKING TOOLS

Tools developed must address diverse patient needs, be culturally/ linguistically appropriate, and cover a broad range of treatment options (Golden et al., 2022; Myers et al., 2021).

- Existing decision support interventions only cover a limited range of treatment options, are too complex, and answer too few patient questions (Myers et al., 2021).

IMPROVED COLLABORATION WITH PRIMARY CARE PROVIDERS

Oncologists need to interact more with primary care; answers to questions during these encounters can trigger a screening or diagnosis discussion.

EXPANDED SCREENING & DIAGNOSIS INITIATIVES

- Address provider knowledge gaps about screening criteria.
- Tackle stigma and patient fears surrounding lung cancer diagnosis.
- Manage expectations on time to diagnosis and diagnosis experience.

DEVELOPING ADVOCACY CAPACITY AMONG PEOPLE LIVING WITH MNSCLC

- The experience of living with NSCLC varies widely and there is a need to engage survivors to better understand how patient priorities may differ from the medical or public health community, particularly in addressing stigma, public involvement, responsibility for sharing stories, and guiding other patients (Dy et al., 2017).
- Clinical spaces can try and engage newly diagnosed patients to help build social connection by providing more information on support groups or increasing access to mental health professionals.
- Visit External Resources on page 21 to see a list of Patient/Caregiver Organizations, Clinical Society Websites, and other resources for more information.

Acknowledgements

The NHC would like to recognize the members of the Advisory Steering committee for their critical review, domain expertise, and iterative feedback, all of which substantially informed the dossier framework and design.

- **Shanada Monestime, PharmD, BCOP –** Director, Community Engaged Research, GO2Lung Foundation
- **Terri Conneran –** Patient, Founder & Director, KRAS Kickers
- **Dusty Donaldson –** Patient Advocate, Founder, Lung Cancer Action Network & LiveLung
- **Annette Eyer –** National Assistant Vice President Media Advocacy and Patient Engagement, American Lung Association
- **Albert Rizzo, MD, FACP –** Chief Medical Officer, American Lung Association
- **Hossein Borghaei, DO, MS –** Chief of Thoracic Medical Oncology, Professor, Department of Hematology/Oncology at Fox Chase Cancer Center
- **Andrea McKee, MD –** Radiation Oncology Associates and Chairman of Radiation Oncology, Lahey Hospital & Medical
- **Upal Basu Roy, PhD, MPH –** Executive Director, Research, LUNGevity
- **Cosmina Hogea –** Senior Director, Gilead Sciences, Inc

This collaboration project was supported by Gilead Sciences, Inc.

External Resources

PATIENT/CAREGIVER ORGANIZATIONS & PEER SUPPORT WEBSITES:

- **American Cancer Society** —Lung cancer guides and fact sheets
- **American Lung Association** —Organization for advocacy, education, and research on lung health
- **Caregiver Action Network** —Organization for advocacy and support of caregivers
- **CancerCare services page** —Includes finding support groups and specialized programs for specific population concerns
- **GO2 for Lung Cancer** services page —Includes connecting to other lung cancer patients, treatment navigation, and financial support
- **Inspire.com** —Resource to find support groups and clinical trials
- **LiveLung** —Lung cancer patient organization focused on education and community
- **Lung Cancer Action Network (LungCAN)** —Association of lung cancer advocacy groups
- **LUNGevity** —Lung cancer organization focused on research, support services, and education
- **National Alliance for Caregiving** —Organization for advocacy, research, and programs for caregivers
- **National Health Council** —Organization of patient groups for chronic disease and disability
- **Smart Patients Lung Cancer Community** —Online support group for patients with lung cancer and their caregivers

CLINICAL SOCIETY WEBSITES:

- **American Society of Clinical Oncology**
- **American Thoracic Society**
- **The American Association for Thoracic Surgery**

OTHER RESOURCES:

- International Association for the Study of Lung Cancer (IASLC) Language Guide. Available from: **https://www.iaslc.org/IASLCLanguageGuide**
- National Comprehensive Care Network. NCCN Guidelines for Patients: Metastatic Non-Small Cell Lung Cancer, 2024. Available from: **https://www.nccn.org/patientguidelines**

Glossary

Activities of Daily Living (ADLs)	Activities of daily living (ADLs) are tasks [patients] do to stay alive and well. Examples include eating, going to the bathroom and moving from place to place. Medical conditions affecting your mind or body can limit your ability to perform ADLs.
Adverse Event(s) (AEs)	An undesired effect of a drug or other type of treatment, such as surgery. Adverse events can range from mild to severe and can be life-threatening. Also called adverse effect and adverse reaction.
Chest CT	A chest CT (computed tomography) scan is an imaging method that uses x-rays to create cross-sectional pictures of the chest and upper abdomen.
Chest X-Ray (CXR)	An x-ray of the structures and organs inside the chest. An x-ray is a type of high-energy radiation that can pass through the body and onto film or a computer, making pictures of areas inside the body. A chest x-ray may be used to help diagnose injuries or diseases that affect the chest.
Diagnosis (Dx)	The process of identifying a disease, condition, or injury from its signs and symptoms. A health history, physical exam, and tests, such as blood tests, imaging tests, and biopsies, may be used to help make a diagnosis.
Epidermal Growth Factor Receptor (EGFR)	Errors in the EGFR gene are one type of lung cancer biomarker. EGFR, which stands for epidermal growth factor receptor, is a protein located on the surface of cells that helps them grow. A mutation in the gene that codes for the EGFR protein can make cells grow too much, which can cause cancer.

Gastrointestinal (GI)	Having to do with the gastrointestinal (GI) tract or GI system. The GI tract includes the mouth, throat, esophagus, stomach, small intestine, large intestine, rectum, and anus.
Health care Provider/ Personnel (HCP)	HCP refers to all paid and unpaid persons serving in health care settings.
Lung Cancer Screening(s) LCS	The only recommended screening test for lung cancer is low-dose computed tomography (also called a low-dose CT scan, or LDCT). During an LDCT scan, you lie on a table and an x-ray machine uses a low dose (amount) of radiation to make detailed images of your lungs.
Metastatic Non-Small Cell Lung Cancer (mNSCLC)	Non-small cell lung cancer (NSCLC) is the most common type of lung cancer. It happens when normal cells in your lungs change and grow out of control. NSCLC grows slowly compared to small cell lung cancer. But it can spread to other parts of your body before you develop noticeable symptoms. Metastasis is when cancer spreads beyond the place where it started to other areas of your body. Nearly all cancers have the potential to metastasize.
Overall Survival (OS)	The length of time from either the date of diagnosis or the start of treatment for a disease, such as cancer, that patients diagnosed with the disease are still alive. In a clinical trial, measuring the OS is one way to see how well a new treatment works. Also called overall survival.
Palliative Care	Palliative care is focused on improving the quality of life for people living with a serious illness like cancer. People with cancer may receive palliative care at any time from the point of diagnosis, throughout treatment, and beyond.

Primary Care Provider/ Physician (PCP)	A doctor or other licensed medical professional, such as a nurse practitioner or physician assistant, who manages a person's health care over time. PCPs diagnose and treat a wide range of common medical conditions. They also provide preventive care, such as disease screenings and immunizations. A PCP may also refer a person to a specialist or coordinate care given by a specialist.
Progression-Free Survival (PFS)	The length of time during and after the treatment of a disease, such as cancer, that a patient lives with the disease but it does not get worse. In a clinical trial, measuring the PFS is one way to see how well a new treatment works. Also called progression-free survival.
Patient-Reported Outcome Measures (PROMs)	PROMs are the tools or instruments used to measure [patient-reported outcomes]. These tools may measure the patient's health status such as health-related quality of life. These tools are often (patient) self-completed questionnaires.
Quality of Life (QoL)	Quality of life (QoL) is a concept that aims to capture the wellbeing of a population or individual regarding both positive and negative elements within the entirety of their existence at a specific point in time. For example, common facets of QoL include personal health (physical, mental, and spiritual), relationships, education status, work environment, social status, wealth, a sense of security and safety, freedom, autonomy in decision-making, social belonging, and physical surroundings.

Stages I – IV (Cancer)

Health care providers use stages of cancer to diagnose disease, make treatment plans and collaborate with other cancer specialists. They base cancer staging on different factors, like tumor size, location, and whether cancer cells have spread to other areas of the body.

- **Stage 0 cancer:** There are abnormal cells, but they haven't spread beyond where they started. Stage 0 can also refer to pre-cancerous cells. Most stage 0 cancers are curable.
- **Stage I (1) cancer:** The tumor is smaller and contained to one area. It hasn't spread to nearby lymph nodes or other areas of the body.
- **Stage II (2) cancer:** The tumor has grown larger and possibly spread to nearby lymph nodes.
- **Stage III (3) cancer:** The tumor has grown deeper into surrounding tissues and has potentially spread to nearby lymph nodes.
- **Stage IV (4) cancer:** Cancer has spread (metastasized) outside of the original site to other organs or distant areas of the body. This is also known as metastatic cancer.

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