



# Human-Centered Design

A Possible  
Solution to Rural  
Clinical Trial Enrollment

Rural cancer patients face barriers to care, including clinical trial enrollment.<sup>1</sup> An understanding of strategies to increase patient enrollment in clinical trials is limited.<sup>2</sup> Incorporating a human-centered design approach to trial development may address the recruitment barriers faced by patients and providers.

Human-centered design is a creative problem-solving method that is increasingly used in health care settings.<sup>3</sup> It is a philosophy based on the discipline of design thinking that addresses issues by putting the end-user experience at the forefront. By keeping the end user in mind, products and services that ignore the needs and context of the users are avoided. The design process begins with an understanding of the affected individuals and develops a product or service centered on their experience. Human-centered design is a collaborative process well suited for complex systems like health care delivery. Human-centered design principles include cyclical rounds of ideation, prototyping, and testing.

Clinical trials are critical to the field of oncology and have enabled revolutionary developments. Over the last few decades, clinical trial design has become increasingly complex, with more narrowly defined patient subpopulations and increased requirements for patient-reported outcome measures, visits, and procedures.<sup>4</sup> The increasing complexity of clinical trials creates undue burdens on participants.

A human-centered approach to designing clinical trials that considers the preferences and experiences of rural cancer patients and providers could increase the number of patients enrolling in trials and help close the health equity gap in rural areas.

Patients and providers are the end users of clinical trials. The increasing complexity of clinical trial enrollment and the increased burden on patients and providers is a barrier to care. We must reexamine our clinical trial infrastructure and consider the patient and provider experience in trial development.

Rural cancer patients face many barriers to care, including limited access to oncology providers, long travel times, and low clinical trial enrollment.<sup>5</sup> A SWOG study revealed that when rural and urban patients have equal access to trials, they experience similar outcomes.<sup>6</sup> Despite established rural clinical trial programs, patients are commonly either ineligible by study criteria or the schedule or travel requirements are too onerous. Rural patients require high-value clinical trials. A human-centered design approach may change the nature of the clinical trials offered and improve trial enrollment among rural patients.


In my rural oncology practice in central Minnesota, clinical trial access was provided to patients through collaborations with larger regional health systems over 2 decades. A team of dedicated clinical trial nurses screened all patients for clinical trial eligibility. The institutional goal was to achieve 1% to 3% clinical trial enrollment; the goal was never reached. Logistical challenges, such as accessing dry ice for laboratory specimen shipment, prevented clinical trial enrollment. Hundreds of patients were screened and found ineligible for trial enrollment. Despite a significant organizational effort to support a clinical trial infrastructure, patients were not adequately enrolled in clinical trials.

Table 1. High-Value Characteristics of Rural-Focused Clinical Trials\*

- Minimal disruption to personal and family life
- Emphasis on advanced-stage diseases
- Access to promising pharmaceuticals in development
- Ability to conduct laboratory and imaging testing locally
- Open-label study design

\*As shared by patients treated at Dr. Swenson's practice.

Over the years, several themes emerged in discussions with my rural cancer patients regarding their interest in clinical trials (Table 1). Rural cancer patients find value in protocols that provide minimal disruption to personal and family life. They value access to promising pharmaceuticals that are otherwise unavailable. They prioritize clinical trials that are focused on advanced-stage diseases. They tend to decline to participate in protocols that require travel for laboratory studies and imaging. They embrace open-label study designs and are often leery of placebo-controlled trials. They are willing to participate in observational trials and are not opposed to telehealth follow-up visits.

A human-centered approach to designing clinical trials that considers the preferences and experiences of rural cancer patients and providers could increase the number of patients enrolling in trials and help close the health equity gap in rural areas. 

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## Introduction

Small cell lung cancer (SCLC) is considered an aggressive form of lung cancer with poor prognosis. It is characterized by rapid and uncontrolled growth of cells in the lungs.<sup>1</sup> Small cell lung cancer has a doubling time as short as 30 days and is notable for rapid metastases to lymph nodes and other organs.<sup>2</sup> Approximately 1 in 4 lung malignancies are small cell lung cancer.<sup>2</sup>

Tobacco use is the primary risk factor for small cell lung cancer.<sup>1</sup> Individuals who smoke have a risk of developing lung cancer that is 10 to 17 times higher than nonsmokers.<sup>2</sup> Increased risk is attributed to the number of cigarettes smoked per day and the number of years smoked. In addition, symptoms vary from person to person, with most individuals presenting with respiratory symptoms (eg, cough, dyspnea) at diagnosis.<sup>3</sup>

Staging is used to define patients with disease limited to thorax only, referred to as limited-stage disease, and small cell lung cancer that has metastasized, referred to as extensive stage disease.<sup>3</sup> Limited-stage small cell lung cancer

is considered curable in approximately 25% of individuals, while extensive stage is considered difficult to treat.<sup>1</sup> Recurrent disease refers to disease that has returned after treatment. Standard treatment varies by stage, options are outlined in **Table 1**.<sup>4</sup>

Although progress has been slow over the past few decades in new treatments for small cell lung cancer, recently there are multiple clinical trials underway examining targeted therapies to treat the disease.<sup>1</sup> The results of which are likely to change the way small cell lung cancer is treated.

## Lessons Learned From Phase I

### Provider and Patient Surveys

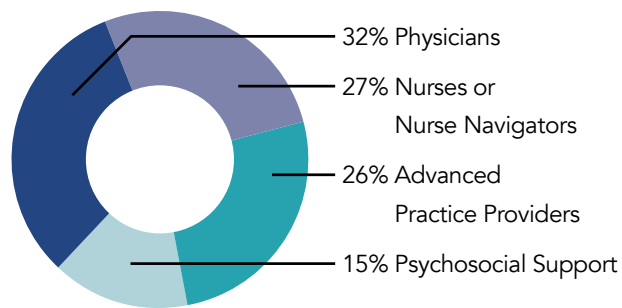
In 2022, the Association of Community Cancer Centers (ACCC) deployed surveys to providers and patients to uncover barriers in obtaining optimal care for patients with small cell lung cancer. The intention was to gain a better understanding of the factors that delay diagnosis and treatment, as well as lead to poor symptom management among patients.<sup>5</sup>

**Table 1.** Standard Treatment Options for Patients With Small Cell Lung Cancer<sup>4</sup>

Stage	Standard treatment options
Limited-stage disease	<ul style="list-style-type: none"><li>• Chemotherapy and radiation therapy</li><li>• Combination chemotherapy alone</li><li>• Surgery followed by chemotherapy or chemoradiation therapy</li><li>• Prophylactic cranial irradiation</li><li>• Clinical trial</li></ul>
Extensive-stage disease	<ul style="list-style-type: none"><li>• Immune checkpoint modulation and combination chemotherapy</li><li>• Combination chemotherapy</li><li>• Radiation therapy</li><li>• Thoracic radiation therapy for patients who respond to chemotherapy</li><li>• Prophylactic cranial irradiation</li><li>• Clinical trial</li></ul>
Recurrent disease	<ul style="list-style-type: none"><li>• Chemotherapy</li><li>• Immune checkpoint modulation</li><li>• Clinical trial</li><li>• Palliative therapy</li></ul>

The provider survey had 100 provider responses. Break out by provider type is shown in **Figure 1**.<sup>5</sup>

**Figure 1.** Percent Response by Provider type<sup>4</sup>



Physicians, advanced practice providers, and nurses or nurse navigators were equally split among working environments. Thirty-four percent (34%) work in community cancer program and 34% work in private practice.<sup>5</sup> By comparison, 47% of psychosocial support providers noted working in a private or physician practice.

The patient survey had 51 respondents.<sup>5</sup> Median patient age was 40 years, and 59% had limited-stage small cell lung cancer. Forty-five percent (45%) of patients held private insurance, 33% were Medicare beneficiaries, 8% had Medicaid, and 2% were under- or uninsured. Racial and ethnic breakup for patients

showed 69% were White, 10% were Black, and 6% were one of the following Asian/Asian American, Hispanic/Latinx, American Indian/Alaska Native, or Native Hawaiian/Pacific Islander.

#### Diagnosis and Management of Small Cell Lung Cancer

Small cell lung cancer, known for its rapid growth and spread to other parts of the body, is important to detect as early as possible. Additionally, clinical presentation can be consistent with pulmonary inflammatory or infectious conditions, leading to delays in appropriate management.<sup>6</sup> ACCC's patient survey, showed patients saw an average of 3 doctors for their symptoms prior to receiving a diagnosis of small cell lung cancer.

The top 3 contributors to a delay in small cell lung cancer by providers is outlined in **Figure 2**. They included biopsy confirmation or pathology results, patient access to care, and scheduling delays such as availability of office appointments.<sup>5</sup>

Quality of life was examined in the provider survey. A good quality of life is defined as the ability to continue daily living or desired activities, achieve goals, and interact with family and friends. Providers reported quality of life as an important factor in making treatment decisions, see **Figure 3**.<sup>5</sup>

**Figure 2.** Provider-Reported Reasons Contributing to Delays in Small Cell Lung Cancer Diagnosis

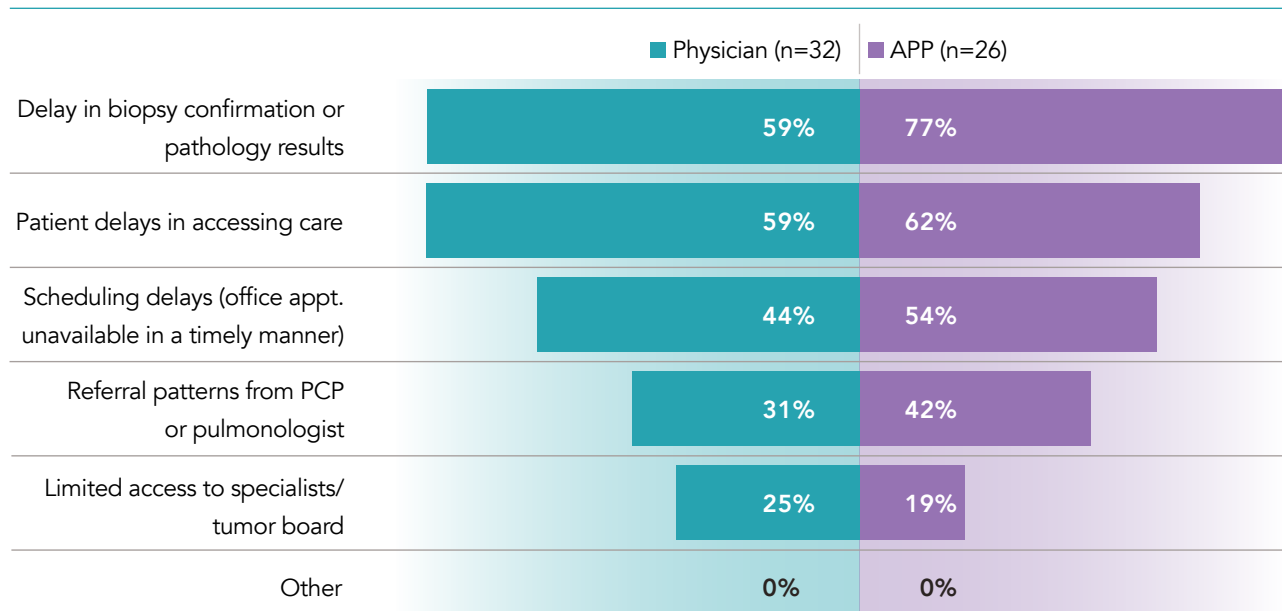
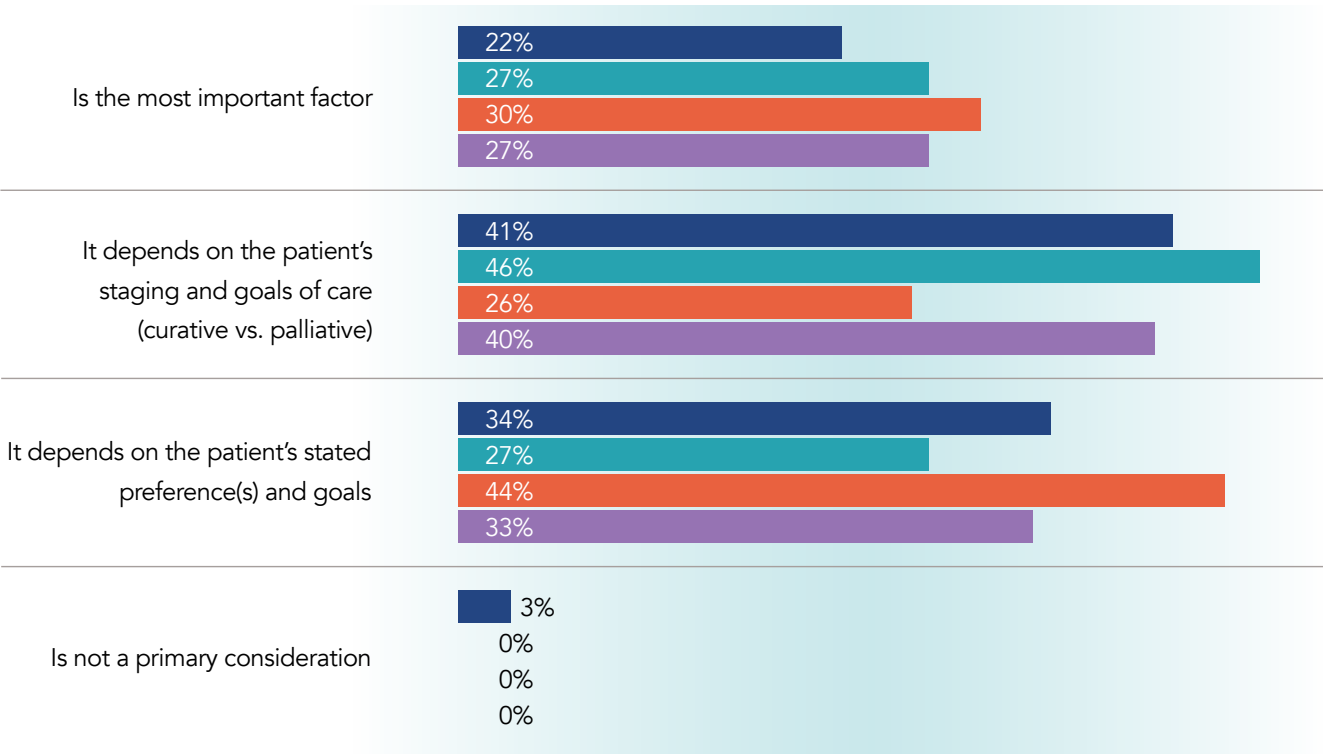


Figure 3. Provider-Reported Role of QOL in Making Treatment Decisions<sup>5</sup>

How significant is patient quality of life when making treatment recommendations?

■ Physician (n=32) ■ APP (n=26) ■ Nurse (n=27) ■ PSS (n=15)



Most providers reported the importance of quality of life in treatment planning was dependent on disease staging, and type of treatment (ie, curative vs palliative).<sup>5</sup>

The patient survey found that patients reported that their quality of life could be improved with support of the following challenges during treatment: management of their pain or any other unwanted symptoms, addressing their psychological well-being, help with logistical aspects of care (eg, financial barriers and living situations), and addressing spiritual or existential suffering.<sup>5</sup>

This disease has a considerable burden on patients, with significant impact on quality of life. Patients with small cell lung cancer often present with symptoms indicating widespread metastatic disease (eg, weight loss, bone pain, and neurologic compromise). Increasing symptom burden has a negative impact on patients' quality of life. ACCC's patient survey identified the most bothersome symptoms of small cell lung cancer, see **Figure 4**.<sup>5</sup>

**Treatment Patterns and Referrals**

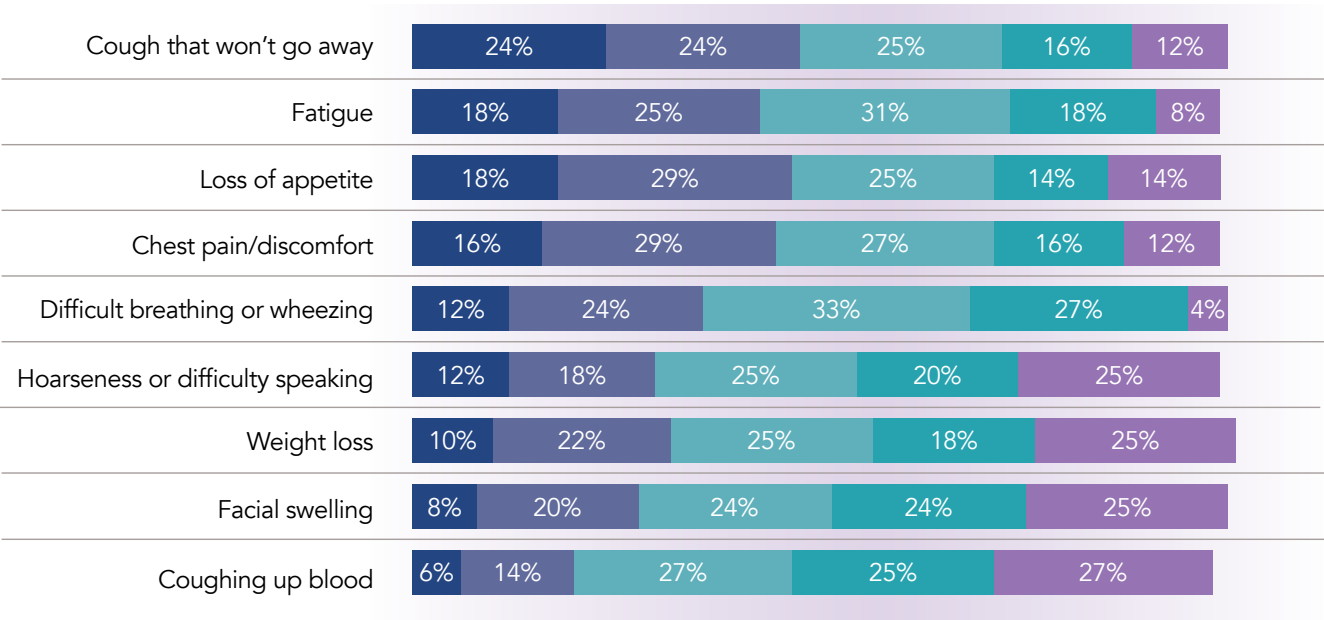
The provider survey examined treatment patterns and clinical trial referrals. Most physicians (51%) and advanced practice providers (67%) said they were highly likely to refer patients to a clinical trial, based on availability.<sup>5</sup> However, it was noted that first-line treatment would be used first. Barriers to clinical trial participation were also identified as lack of trial availability, lack of transportation or other logistical barriers, patient preference, narrow inclusion criteria, and need for more immediate treatment.

For treatment of patients with extensive-stage small cell lung cancer, providers noted that 80% of patients receive a platinum doublet plus atezolizumab or durvalumab as first-line therapy.<sup>5</sup> For the 18% of patients who receive chemotherapy only as first-line treatment, providers noted, autoimmune disorders, prior allergies, and cost concerns were reasons for doing so. Providers also noted that 4% of patients with extensive-stage small cell lung cancer did not receive first-line treatment due to fac-

Figure 4. Patient-Reported Frequency of Symptoms<sup>5</sup>

How often are each of the following potential symptoms of SCLC bothersome to you?

■ Multiple times per day ■ Daily ■ Weekly ■ Present, but bothers me less than once per week ■ Not present



**Other symptoms related to SCLC**

Sleep issues/tired/weakness **8%** | Back/spine pain/localized pain **6%** | Trouble eating/weight loss **6%** | Fever **3%** | Blood issues/bleeding **3%** | Inflammation/swelling **3%**

tors such as poor performance status, multiple comorbidities, and patients' decision to choose palliative care.

An examination of second-line treatment found 13% of physicians, and 20% of advanced practice providers reported that less than or equal to 50% of their patients with extensive-stage small cell lung cancer initiated second-line treatment at disease progression.<sup>5</sup> The physician survey found many factors at play when considering whether to recommend platinum-based rechallenge when choosing subsequent systemic therapy for patients with small cell lung cancer. These include degree and duration of first response, patient performance status and organ function, as well as number of comorbidities. Barriers to second-line treatment were identified as patient fitness, management of treatment-related adverse events, and the presence of multiple comorbidities.

**Support Services**

The physician survey found that education and information shared with patients, including an explanation of the diagnosis, answering questions, providing educational handouts and trusted internet resources, and providing referrals to supportive care services, was most often done by advanced practice providers, nurses, and psychosocial support providers.<sup>5</sup>

In addition, physicians reported patient referrals to palliative or supportive care occurred at various stages during treatment. This includes after failure of multiple lines of therapy, upon first recurrence or refractory disease, at diagnosis, or when symptoms become difficult to manage or are uncontrolled. Comparatively, advanced practice providers noted referring patients to supportive services when symptoms became difficult to manage or after multiple lines of therapy.



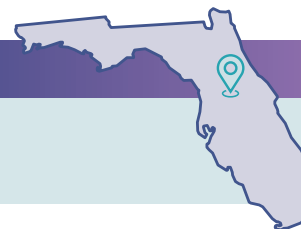
## Best Practices

In addition to the patient and providers surveys, ACCC examined best practices in treatment of small cell lung cancer. The following cancer programs highlight best practices in specific areas of cancer care.

### AdventHealth Cancer Institute Waterman

**LOCATION:** Tavares, Florida

**EFFECTIVE PRACTICE:** Patient Navigation and Community Partnerships



AdventHealth Cancer Institute Waterman (Advent Waterman) established a lung nodule clinic to further streamline the diagnosis of lung cancer after a positive screen and reduce delays in the assessment of incidental nodules. As a result, the lung navigator's role expanded to support the lung nodule clinic and connection to the cancer treatment team.

**Next Steps:** AdventHealth Waterman has a strong, skilled multidisciplinary team committed to caring for patients impacted by small cell lung cancer. Moving forward, the team at AdventHealth aims to grow the lung cancer screening program and lung nodule clinic and expand community partnerships to support patients across the lung cancer continuum.

"Navigation is key. Capturing patients up front, helping them figure out their next step is critical. Then getting patients to the right specialist at the right time whether through the lung nodule clinic or connecting them to our multidisciplinary cancer care team—navigation is the glue that holds the process together. Plus, the clinical outcomes that can be addressed are substantial."

— **Leslie K. Maxwell, MBA,**  
Director,  
*AdventHealth Cancer Institute Waterman*

### Corewell Health

**LOCATION:** Taylor, Michigan

**EFFECTIVE PRACTICE:** Timely Diagnosis to Treatment Initiation



Corewell Health's lung clinic includes a multidisciplinary provider team comprised of pulmonologists, interventional pulmonologists, nurses, a nurse coordinator, a clinical nurse manager, lung cancer nurse navigators, a cardiothoracic surgeon, oncologists, radiation oncologists, and many more providers and staff who play a critical role in ensuring quality, patient-centered care. The lung clinic has a strong referral network, and typically receives 25 to 50 referrals a week for diagnostic workup. The team works together to triage patients and get them in as quickly as possible.

**Next Steps:** Building on the strong foundation, Corewell Health is investing in additional diagnostic tools and research to improve outcomes of patients impacted by lung cancer. The team hopes the innovative work they

are doing in Michigan will be able to be replicated across the country for all patients.

"Start simple. What is it that you are intending to do? Are you intending to optimize your diagnostics? Are you attempting to accelerate recovery? Are you attempting to improve your therapeutics? Or something else? Then decide how do you get your toe in the water, and then you must crawl before you walk, and you must walk before you sprint. But collective intelligence is going to be the key for success."

— **Gustavo Cumbo-Nacheli, MD, FCCP, DAABIP**  
Interventional pulmonologist,  
*Corewell Health*



## Levine Cancer Institute

**LOCATION:** : Charlotte, North Carolina

**EFFECTIVE PRACTICE:** Comprehensive Support Program



The Levine Cancer Institute's Cancer Committee identified an opportunity to improve support for patients who receive a diagnosis of lung cancer. Levine sees a wide range of people impacted by lung cancer. Each year, the Health System diagnoses 900 new cases of lung cancer, with approximately 150 cases representing small cell lung cancer. The cancer committee coalesced around a lung cancer support program. A thoracic medical oncologist championed the initiative and assembled a passionate and committed multidisciplinary team including a physical and occupational therapist, music therapist, psychologist, patient resource manager, nurse navigators, nutritionist, social worker, research scientist, and program coordinators.

**Next Steps:** Levine Cancer Institute now has a solid foundation in place to provide ongoing support to people impacted by lung cancer. There remains a commitment from the multidisciplinary team to continue to innovate and build out additional services to meet patients' needs.

"In my experience, people living with lung cancer commonly feel their needs are not recognized. I am proud of the fact we started a support program for patients with lung cancer to show we do care, and we can offer tailored services based on the patient's type of lung cancer."

— Michele Szafranski, MS, RD, CSO, LDN

Clinical nutrition manager,  
Levine Cancer Institute

## White Plains Hospital Cancer Program

**LOCATION:** : White Plains, New York

**EFFECTIVE PRACTICE:** Whole-Person Care



All patients receiving lung cancer care at White Plains Hospital Cancer Program are presented at the multidisciplinary thoracic tumor board, which meets 2 to 3 times a month. Patients are also quickly connected to a medical oncologist and the multidisciplinary team works to meet patients' needs beyond the disease itself across the care continuum. The White Plains team knows any cancer diagnosis and its treatment can significantly impact patients' quality of life. Therefore, the team has taken a whole-person approach to the structure of the infusion center. The infusion center is nursing led; nurse practitioners round regularly and follow their patients to ensure continuity of care and early intervention.

**Next Steps:** The team remains committed to their approach, while also identifying new opportunities, such as expanding its partnership with the American Lung Association, piloting a new palliative care model, and offering increased transportation services to reduce barriers to care.

"Our infusion center is not just a place for the delivery of treatment. It is an opportunity for us to try and make our patients' day a little easier by providing whole-person care during that time."

— Victoria Assumma, LCSW-R, ACSW, OSW-C

Oncology social worker,  
White Plains Hospital Cancer Program

## David M. Waterhouse, MD, MPH, Oncologist

**LOCATION:** Cincinnati, Ohio

**EFFECTIVE PRACTICE:** Clinical Trials



David M. Waterhouse, MD, MPH, a medical oncologist, has been leading the charge in lung cancer clinical trials for decades. While clinical trials for small cell lung cancer have not moved forward in the same way as trials in other disease areas, Waterhouse offers systems-level solutions to change how trials are conducted and leverage underutilized resources:

- Design trials that are patient centric. For small cell lung cancer, change enrollment criteria and allow patients to be enrolled even after the first dose of chemotherapy, eliminate central lab and radiology reviews, and be more pragmatic about what data is necessary to collect.
- Use lessons learned from the COVID-19 pandemic such as electronic consent, remote monitoring, delivery of treatment to home, home nurse visits, and telemedicine encounters.

- Centralize trial coordination, investigator support, consent, and other necessary research operations while decentralizing the delivery of the treatment.
- Build hybrid partnerships between academic and community programs.
- Reimburse for providers' time spent on a trial whether through a Medicare designation or J-code.

Waterhouse also stresses the importance of mentorship to foster and support researchers in building clinical trial capacity.

**"Eighty-five percent of cancer care is delivered in the community. The question we should be asking is— how can we develop trials that are community-centered? Trials need to reflect the world we see, not the world we can treat."**

**— David M. Waterhouse, MD, MPH**

## Clinical and Nonclinical Challenges in Treatment

### Clinical Challenges

Clinical challenges affecting care for patients with small cell lung cancer are numerous. Patients often have significant comorbidities such as chronic obstructive pulmonary disease, cardiovascular disease, or diabetes. These preexisting comorbidities complicate a patient's ability to tolerate treatment, and may shorten their overall survival.<sup>8</sup> Additionally, because of the rapid growth of small cell lung cancer, it presents as a centrally located mass that can obstruct major airways and lead to rapid clinical decline.

There are also concerns with small cell lung cancer treatments. Platinum-doublet chemotherapy, although highly effective in the initial treatment of small cell lung cancer, also has the potential to be very toxic to patients. This

with poor performance status at baseline. Key findings from the ACCC survey found treatment-related adverse events were the greatest deterrent to receiving the best possible small cell lung cancer care among patients.

In addition to side effects attributable to traditional chemotherapy, providers need to be cautious of immune-related adverse events (irAEs). The most frequently reported irAEs are hypothyroidism, hyperthyroidism, rash, and colitis.<sup>9</sup> However, any organ system can be subject to autoimmune damage from immunotherapy use. To facilitate appropriate clinical management of irAEs, cancer providers should equip patients with immunotherapy "wallet cards" that can be presented to non-oncology providers with clear contact information for the oncology team.<sup>10</sup> Additionally, patients should be instructed to inform their routine nononcology providers (ie, primary care provider, pulmonologist) if they are receiving immunotherapy.

## Nonclinical Challenges

In addition to clinical challenges, health care providers and patients face nonclinical challenges in the management of small cell lung cancer. Nonclinical challenges include financial barriers, psychosocial issues, inadequate support systems, among others. The ACCC survey showed little consensus among physician providers in identifying the most significant barriers to providing optimal care to patients with small cell lung cancer.<sup>5</sup> Top nonclinical barriers were identified as inadequate support systems, cost of care, and lack of transportation. Other hurdles were identified as poor health literacy, difficulty comprehending diagnosis, lack of access to treatment, family care considerations, and difficulty communicating with the health care team.

Financial barriers are often among the top challenges encountered by cancer patients. With the recent addition of immunotherapy to the treatment of small cell lung cancer, there is also a new layer of financial burden. Specifically, because immunotherapies can be given as maintenance therapy until disease progression or unacceptable toxicity. In the ACCC survey, physicians, more than any other provider, found treatment cost and location (ie, at home vs in clinic) to be less significant to patients in their treatment choice compared to other factors, such as overall survival or adverse events from treatment.<sup>5</sup>

Nurses, however, consistently perceived treatment cost, treatment location, and number of office/lab visits for ongoing treatment monitoring, to have more impact on a patients' treatment choice. In the ACCC patient survey, approximately one-third reported out-of-pocket costs or surprise bills were considered an extreme problem.<sup>5</sup> Financial counselors or navigators can be a great resource to guide patients through the financial difficulties of treatment by overseeing insurance authorizations and providing co-pay assistance.<sup>11</sup>

Other nonclinical challenges include stigmatization, psychological well-being, equitable care, and health literacy levels. Study results show that lung cancer stigma can result in deterred screening, delayed diagnosis, and severe psychosocial distress.<sup>12</sup> Along with potential stigmatization, psychological well-being and spiritual/existential suffering are also pervasive among patients

with small cell lung cancer. The ACCC patient survey found 20% reported spiritual/existential suffering as a substantial hardship, and 35% reported that support for psychological well-being was the most important aspect in assisting with treatment challenges.<sup>5</sup>

In addition, the patient survey found 30% indicated difficulties understanding medical language which significantly hindered optimal care.<sup>5</sup> Discussions about diagnosis and treatment should always be conducted at a health literacy level appropriate to the patient to foster productive conversations and shared decision-making. Similarly, to better understand disparities, health care team members should complete a cultural competency training to recognize their own implicit biases in communicating with patients.

## Multidisciplinary Care

Due to the rapid growth of small cell lung cancer, prompt diagnosis and treatment are vital and depend on the collaboration of various providers. Management of patients with small cell lung cancer is not possible without a dedicated multidisciplinary team consisting of medical oncologists, radiation oncologists, pulmonologists, primary care providers, pathologists, thoracic surgeons, nurses, advanced practice providers, pharmacists, palliative care providers, social workers, financial navigators, among others.<sup>13</sup> Primary care providers and pulmonologists must be able to recognize symptoms associated with small cell lung cancer and to refer patients efficiently to medical oncologists and/or thoracic surgeons. Treatment decisions are best discussed in a multidisciplinary tumor board with input from different specialties.

Patients with small cell lung cancer are often hospitalized due to the acuity of their symptoms, which means that coordination of care between inpatient and outpatient teams is critical. To assist with treating symptoms, primary oncologists should refer patients to palliative care teams, radiation oncologists, and interventional pulmonology teams for consideration of palliative procedures and interventions. Ancillary team members, such as social workers and financial navigators, can support patients in managing nonclinical barriers to care.

## Conclusion

In a post-COVID-19 era, cancer programs have seen a significant decrease in lung cancer screening, diagnosis, and treatment.<sup>14</sup> This is particularly impactful for those with small cell lung cancer due to the aggressive nature of the disease. To address the specific needs of these patients, ACCC engaged in a multiphased educational initiative to address the challenges and burdens faced by patients with small cell lung cancer in community oncology programs and practices.

The first phase of this project focused on survey data collection and identifying barriers and gaps in care. To accomplish this, ACCC deployed surveys to providers and patients to uncover barriers in obtaining optimal care for patients with small cell lung cancer. After successful completion of the surveys, quality-of-life challenges experienced by patients with small cell lung cancer were examined. ACCC collected best practices on comprehensive care for small cell lung cancer to share with member cancer centers. The results of both are shared in this article among other published resources.

ACCC is dedicated to ensuring cancer programs have the knowledge and shared best practices to support all patients on their cancer journeys.

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In partnership with:



This project is supported by:



A publication from the ACCC education project, "Comprehensive Quality Care for Patients with Small Cell Lung Cancer." Learn more at [accc-cancer.org/comprehensive-sclc-care](http://accc-cancer.org/comprehensive-sclc-care).

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