Lung Cancer
Specialty Registry Report 2017

What is the Lung Cancer Specialty Registry?

Lung cancer is the leading cause of cancer death, regardless of gender or ethnicity, accounting for more cancer-related deaths than colon, breast, and prostate cancers combined. Yet, thanks to earlier diagnosis and personalized treatment, people are living longer. Approximately 220,000 new lung cancer diagnoses are expected in 2017 (SEER). There are two main types of lung cancer: non-small cell lung cancer, representing 85% of all cases and small cell lung cancer. Each type requires different treatment regimens and has a different prognosis.

The Lung Cancer Specialty Registry, which began accepting participants in December 2014, documents the experiences of a cross-section of people living with lung cancer. The Lung Cancer Advisory Council—made up of lung cancer specialists and other oncologists, behavioral scientists, patient advocates, and industry representatives—supports the efforts of the Registry by providing continued support and guidance on outreach, research, and the dissemination of findings (see a list of Advisory Council members at **www.cancersupportcommunity.org/RegistryIndexReport2017**).

CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope
GILDA'S CLUB WORLDWIDE
the wellness community

KEY FINDINGS

THIS REPORT CONTAINS NUMEROUS INSIGHTS
INTO THE LUNG CANCER EXPERIENCE. KEY FINDINGS INCLUDE:

QUALITY OF LIFE

52%
ARE AT RISK FOR CLINICAL DEPRESSION

51%
REPORT WORSE PHYSICAL FUNCTIONING

21%
REPORT WORSE PAIN THAN THE NATIONAL AVERAGE

25%
OF LUNG CANCER SURVIVORS RATE THEIR OVERALL HEALTH AS VERY GOOD OR EXCELLENT

TREATMENT DECISION-MAKING

92%
OF PATIENTS IN SECOND-LINE THERAPY OR LATER FELT MORE KNOWLEDGEABLE THAN THEY DID DURING FIRST-LINE THERAPY

50%
LUNG CANCER RESPONDENTS REPORT NOT BEING TESTED FOR GENETIC MARKERS

72%
WERE INVOLVED IN TREATMENT DECISION-MAKING, ONLY 36% FELT PREPARED TO MAKE A DECISION

PSYCHOSOCIAL IMPACT

34%
BELIEVE OTHERS THINK HAVING LUNG CANCER IS THEIR FAULT

61%
ARE CONCERNED ABOUT FEELING TOO TIRED AND

57%
ARE WORRIED ABOUT THE FUTURE AND WHAT LIES AHEAD

STIGMA IS AN ISSUE

30%
REPORT FEELING GUILTY BECAUSE OF THEIR DIAGNOSIS

FINANCIAL IMPACT

31%
DID NOT TALK ABOUT COSTS OF TREATMENT WITH A MEMBER OF THEIR HEALTH CARE TEAM

36%
REPORT SIGNIFICANT LEVELS OF INTRUSIVE THOUGHTS AROUND MANAGING THE COSTS OF CANCER CARE

24%
SPENT OVER $500 IN MONTHLY OUT-OF-POCKET COSTS RELATED TO THEIR LUNG CANCER CARE

Who is in the Registry?

This 2017 report presents analysis from 291 lung cancer patients who reside in the United States and completed survey questions from the opening of the Registry in December 2014 to December 31, 2016 (in the tables below, number of responses is 291 unless otherwise noted).

FIGURE 1 **LUNG CANCER REGISTRY SURVEY DEMOGRAPHICS**

	NUMBER OF PARTICIPANTS (n)	*PERCENT*
AGE	(n = 175)	
Mean age	60 years, SD = 11	Range: 25 to 87
18-44	15	9%
45-64	105	60%
>=65	55	31%
GENDER	(n = 148)	
Male	47	32%
Female	100	67%
RACE	(n = 148)	
White	124	84%
Black or African American	9	6%
NON-HISPANIC ETHNICITY	(n = 148)	
	131	88%
EDUCATION	(n = 148)	
High school or less	31	21%
Associate degree or some college	54	37%
Bachelor degree	27	18%
Graduate degree or higher	34	23%
REGION	(n = 138)	
Urban	32	20%
Suburban	76	47%
Rural	44	27%
EMPLOYMENT STATUS	(n = 138)	
Full-time	20	15%
Part-time	10	7%
Retired	54	39%
Not employed due to disability	43	31%
Not employed (reason not specified)	11	8%
ANNUAL INCOME	(n = 135)	
<$40K	38	28%
$40-59.9K	15	11%
$60-79.9K	17	12%
$80-99.9K	5	4%
$100K+	13	10%
Prefer not to share	42	31%

FIGURE 2 CANCER STAGE, TIME SINCE DIAGNOSIS AND CANCER STATUS OF SURVEY PARTICIPANTS

	NUMBER OF PARTICIPANTS (n)	*PERCENT*
STAGE AT DIAGNOSIS	(n = 117)	
Stage I	25	21%
Stage II	12	10%
Stage III	26	22%
Stage IV	45	39%
I don't know	9	8%
TIME SINCE DIAGNOSIS	(n = 118)	
<1 year	18	16%
1–1.9 years	31	26%
2–4.9 years	44	37%
>=5 years	25	21%
METASTATIC	(n = 120)	
	57	48%
RECURRENCE	(n = 120)	
	31	26%

What are we learning?

DIAGNOSTIC EXPERIENCE

Non-small cell lung cancer (NSCLC) respondents made up 84% of survey respondents; among those, 65% were diagnosed with adenocarcinoma, 16% with squamous cell carcinoma, and 4% with large cell carcinoma; 14% did not know the type. Small cell lung cancer patients made up 16% of survey respondents. Recent science has identified a number of genetic markers for lung cancer. Half (50%) of lung cancer respondents reported not being tested for genetic markers. Of those tested, 37% indicated their tumor proved positive for the EGFR mutation. As for other common genetic markers, 9% tested positive for KRAS, 6% for ALK translocation, and 3% for ROS1 translocation. A significant proportion (20%) tested negative for all markers. Eighty-six percent indicated their diagnosis did not result from a cancer screening of any kind. Instead, 50% reported their diagnosis occurred after experiencing symptoms.

> Half of patients said they were not screened for genetic markers. Molecular tumor testing is important as research continues to develop treatments targeting these specific types of tumors.

PERCEPTIONS ABOUT HEALTH

Twenty-five percent of respondents described their overall health as excellent or very good, but nearly half (45%) reported they were in fair or poor health (Figure 3).

CANCER-RELATED DISTRESS

Lung cancer can be associated with significant emotional distress. Figure 4 presents the 10 items that most respondents were moderately, seriously, or very seriously concerned about according to **CancerSupportSource**®, a validated distress screening instrument.[1]

CancerSupportSource features a depression subscale which demonstrated that just over half (52%) of lung cancer respondents were at risk for clinical depression.

QUALITY OF LIFE

Quality of life is of key concern to lung cancer patients. The Lung Cancer Specialty Registry incorporates the PROMIS-29, which compares how patients describe their quality of life compared to other U.S. population groups across seven different areas of life.[2] As Figure 5 illustrates, many lung cancer patients reported substantially worse quality of life than the national average for physical functioning (51% of respondents), fatigue (35%), anxiety (32%), social functioning (31%), and depression (25%). In addition, 21% of respondents reported worse pain interference and 9% reported worse sleep disturbance.

LUNG CANCER-RELATED STIGMA

Because lung cancer is often linked to smoking, many patients—even those who have never smoked—experience stigma associated with their diagnosis. Lung cancer respondents' perceptions of social stigma are featured in Figure 7.

TREATMENT DECISION-MAKING AND PLANNING

Lung cancer patients face a range of complex treatment options after diagnosis. In the survey, 41% of respondents indicated they were in what is called first-line therapy, where they are given drug treatment for the first time. However, 53% reported being in second, third, or even later line therapies. These treatments are assigned when previous therapies were unsuccessful or simply stopped working. Most (87%) reported they see a medical oncologist most often for their treatment, and 4% a radiation oncologist.

FIGURE 3 **SURVEY PARTICIPANTS' PERCEIVED OVERALL HEALTH**

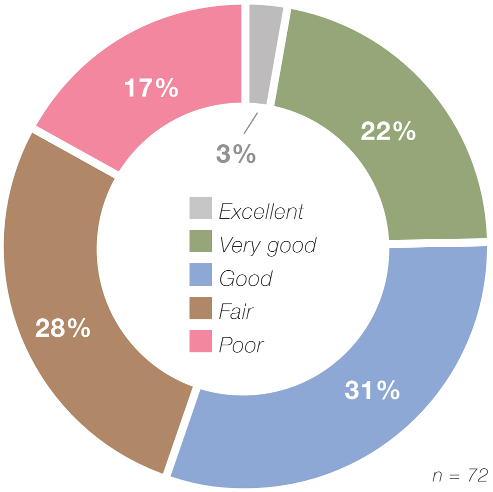
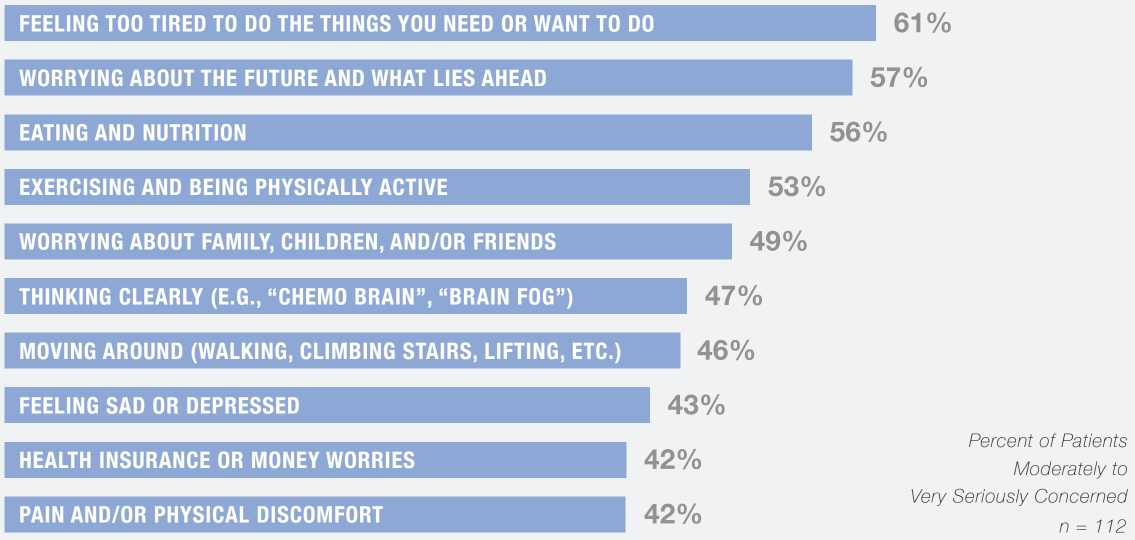


FIGURE 4 **TOP 10 CONCERNS OF LUNG CANCER PARTICIPANTS**



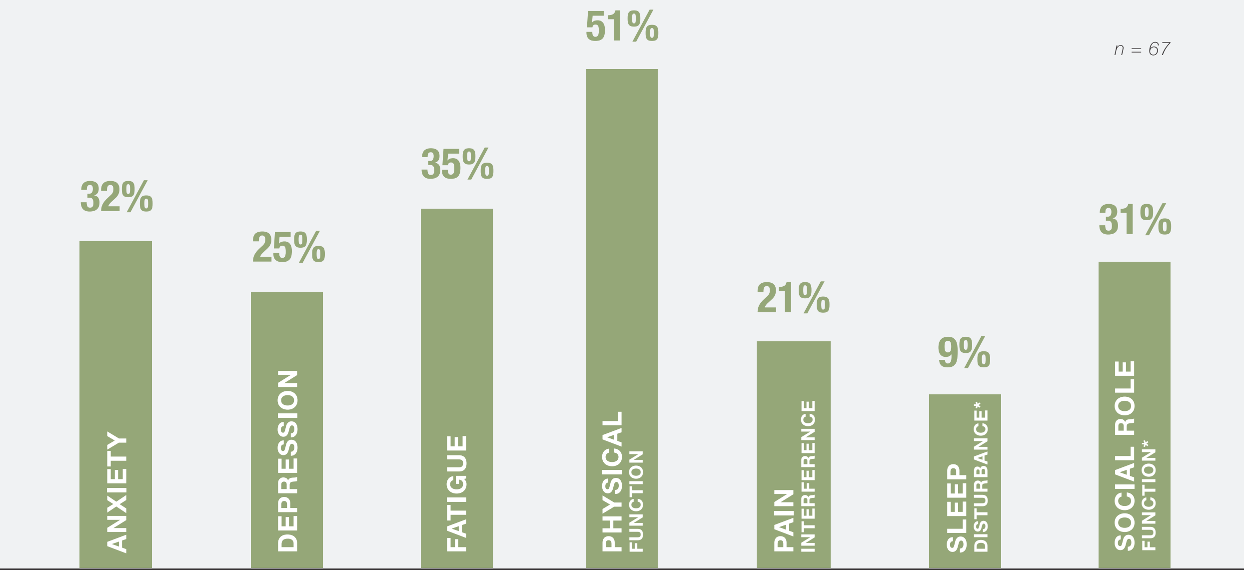


FIGURE 5 **PERCENT OF LUNG CANCER SURVIVORS REPORTING WORSE QUALITY OF LIFE**

*Note: All comparisons are vs. general U.S. population, except where * denotes comparison to U.S. population group balanced to include more people with chronic illness. Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than the respective comparison group.*

Doctor-patient relationships play a large part of any treatment plan. The more patients are aware of the options available to them and the risks and side effects associated with their therapy, the more comfortable the relationship. Although patients are very involved in treatment decision-making, they are far less likely to report feeling knowledgeable about treatment options or prepared to discuss treatment options with their doctor (Figure 6). Maintenance therapy is the ongoing use of

> Ninety-two percent of patients in second-line therapy or later felt more knowledgeable than they did during first-line therapy; 88% of them attributed their increased knowledge to having more experience, and 66% to having access to more information.

FIGURE 6 **TREATMENT DECISION-MAKING PROCESS: LUNG CANCER**

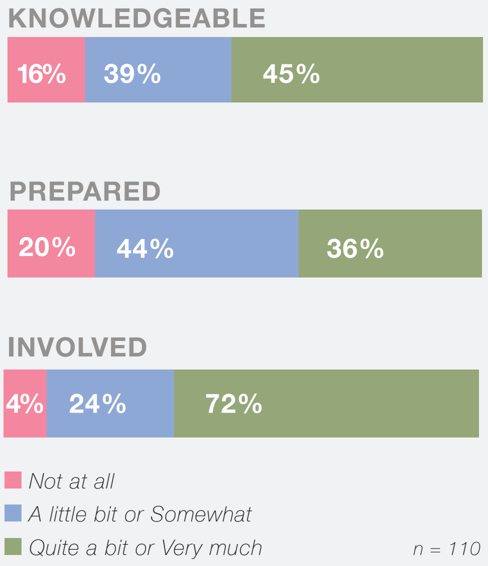
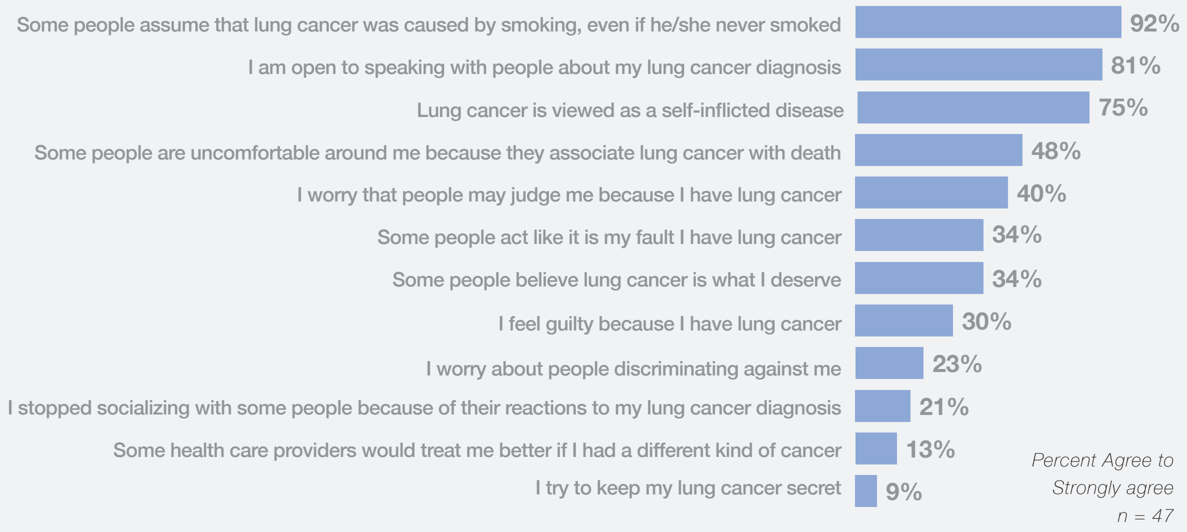


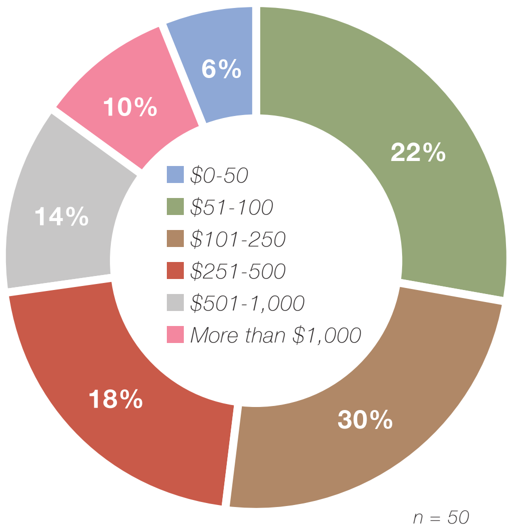
FIGURE 7 **PERCEIVED SOCIAL STIGMA AND LUNG CANCER**



Percent Agree to Strongly agree

n = 47

FIGURE 8 **LUNG CANCER MONTHLY OUT-OF-POCKET COSTS**



n = 50

chemotherapy to minimize the risk of recurrence following the initial therapy. Approximately 62% of lung cancer patients in the survey reported their physician had not discussed maintenance therapy as a treatment option.

COST OF CARE

Apart from treatment, side effects, relationships with family and friends, and managing the disease itself, there is also a financial burden to cancer care that can cause tremendous anxiety. Thirty-six percent of lung cancer respondents reported significant levels of intrusive thoughts about their ability to manage costs of their cancer care, according to the Impact of Events Scale[3]. Thirty-one percent of respondents did not discuss costs with a member of their health care team.

Insurance coverage can mask the monetary impact that patients experience on a regular basis. Many respondents were able to quantify monthly out-of-pocket costs related to their cancer (Figure 8).

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Learn More

For more information and to see our other specialty reports please visit:
www.cancersupportcommunity.org/RegistryIndexReport2017

- Breast Cancer Specialty Registry Report
- Caregiver Specialty Registry Report
- Chronic Lymphocytic Leukemia (CLL) Specialty Registry Report
- Chronic Myeloid Leukemia (CML) Specialty Registry Report
- General Registry Report
- Melanoma Specialty Registry Report
- Metastatic Breast Cancer Specialty Registry Report
- Multiple Myeloma Specialty Registry Report
- Prostate Cancer Specialty Registry Report
- Stomach Cancer Specialty Registry Report

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2. Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S.,…Hays, R. D. on behalf of the PROMIS Cooperative Group. (2010). Initial item banks and first wave testing of the Patient–Reported Outcomes Measurement Information System (PROMIS) network: 2005–2008. *Journal of Clinical Epidemiology*, *63*(11), 1179-94.

3. Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. *Psychosomatic Medicine*, *41*(3), 209-218.

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