

2015 FACES OF LUNG CANCER REPORT



THE LUNG CANCER AVALANCHE.

**ONE PATIENT, ONE DIAGNOSIS,
COUNTLESS CASUALTIES.**



**LUNG
CANCER
CANADA**

AWARENESS. SUPPORT. EDUCATION.

THE FACES OF LUNG CANCER REPORT

NOVEMBER 2015

LUNG CANCER TAKES THE LIVES OF MORE CANADIANS THAN BREAST, PROSTATE, AND COLORECTAL CANCERS COMBINED.

When a patient receives a lung cancer diagnosis in Canada, it triggers an avalanche that devastates and impacts countless lives and systems in its path. While patients, families, caregivers, and healthcare providers continue to remain steadfast in their dedication and fight against lung cancer, the treatments, services, support, and compassion available only go so far to provide hope for those struggling under the weight of this disease.

In our second annual report, the **Faces of Lung Cancer**, Lung Cancer Canada takes an up-close and personal look at Canada's most common and deadly cancer, lung cancer.¹ The unfortunate reality is that **lung cancer takes the lives of more Canadians than breast, prostate, and colorectal cancers combined.**

In addition to claiming lives, the cost of treating patients with lung cancer continues to place a significant burden on the Canadian healthcare system. Lung cancer remains a high-fatality cancer, with a low five-year survival rate of 17%.¹

Several disparities in the diagnosis and treatment of lung cancer exist across Canada and within each province, and these remain unaddressed. **Lung cancer literacy and empathy are low across the country, resulting in many misconceptions about this disease.** A 'blame the victim' mentality means a heavy stigma is attached to lung cancer patients, who are often told "well, you smoked, what did you expect?"

Fighting this disease requires the courage of a patient plus a team of dedicated healthcare professionals and a support system made up of the individual's close family and friends. However, the **cost of caregiving to the caregiver is substantial, largely overlooked, and not adequately captured.** The societal and economic impact of lung cancer is a **leading drain on the global economy**, and is more than breast and colon cancer combined (John RM, Ross H. Economic value of lives lost to cancer, 2008. American Cancer Society/Livestrong 2010). Furthermore, lung cancer in Canada is not only neglected as a funding priority for research, but also as a cause worthy of support and compassion. **Because lung cancer awareness is low, the avalanche caused by a diagnosis is silent and all too often remains unheard.**

Simply put, lung cancer needs to overcome many obstacles to ensure that every Canadian citizen diagnosed with, or at risk of lung cancer has hope and an equal chance to beat this disease. The **Faces of Lung Cancer** report aims to **give a voice to lung cancer patients and their caregivers by informing the public on the status of lung cancer in Canada and providing awareness and education about the various disparities that exist.** In the preparation of this report, we conducted a national review of healthcare services available to those affected by lung cancer and surveyed patients and caregivers to gain more insight about their experiences. This edition of The Faces of Lung Cancer is unique in that for the first time, it provides insight into the perspectives of caregivers on caring for lung cancer patients, as well as the effect that their altruistic behaviour has on their own lives.



THE FACES OF LUNG CANCER

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COMPLETING THE CIRCLE OF CARE

PART 1

A DAILY SNAPSHOT OF LUNG CANCER IN CANADA:

SEVENTY-THREE CANADIANS TOO MANY



EVERY DAY, 73 CANADIANS RECEIVE A LUNG CANCER DIAGNOSIS¹

Lung cancer is the **most commonly diagnosed cancer in Canada**, representing about **14% (1 in 8)** of all new cancer cases in both women and men.

Every hour, three Canadians join the **26,600** new lung cancer cases diagnosed annually

- **13,000** new cases in **women**
- **13,600** new cases in **men**

Estimated number of new lung cancer cases by gender and province, 2015¹

	Canada	BC	AB	SK	MB	ON
Total	26,600 (14%)*	3,150 (12%)	2,150 (13%)	770 (14%)	890 (13%)	9,000 (12%)
Male	13,600 (14%)	1,550 (12%)	1,100 (12%)	360 (13%)	430 (13%)	4,600 (12%)
Female	13,000 (13%)	1,600 (13%)	1,050 (13%)	410 (15%)	460 (14%)	4,400 (12%)

	QC	NB	NS	PE	NL	
Total	8,300 (17%)	810 (16%)	960 (15%)	135 (15%)	470 (13%)	
Male	4,300 (17%)	430 (15%)	480 (14%)	75 (15%)	280 (14%)	
Female	4,000 (16%)	380 (16%)	480 (16%)	60 (15%)	190 (12%)	

* Represents lung cancer as a percentage of the total cancer segment. For example, 12% of all males diagnosed with cancer in BC will be lung cancer diagnoses.

OF ALL CANCERS, LUNG CANCER IS THE BIGGEST KILLER IN CANADA

IT IS ESTIMATED THAT **20,900** CANADIAN LIVES WILL BE LOST TO LUNG CANCER THIS YEAR

- This means that:
 - Every day, 57 Canadians will die from lung cancer
 - Every hour, the lives of more than two Canadian mothers, fathers, sisters, brothers, husbands, wives, and friends will be lost
- Lung cancer accounts for more than 25% of all cancer related deaths in Canada
 - One in 13 Canadian men and one in 17 Canadian women have a lifetime chance of dying from lung cancer
 - In contrast, one in 27 Canadian men have a chance of dying from prostate cancer and one in 30 Canadian women have a chance of dying from breast cancer
- At 17%, lung cancer still has the **lowest five-year survival rate** of all major cancers in Canada
 - Five-year survival rates for prostate, breast, and colorectal cancers are 95%, 88%, and 64%, respectively



Estimated number of lung cancer deaths by gender and province, 2015¹

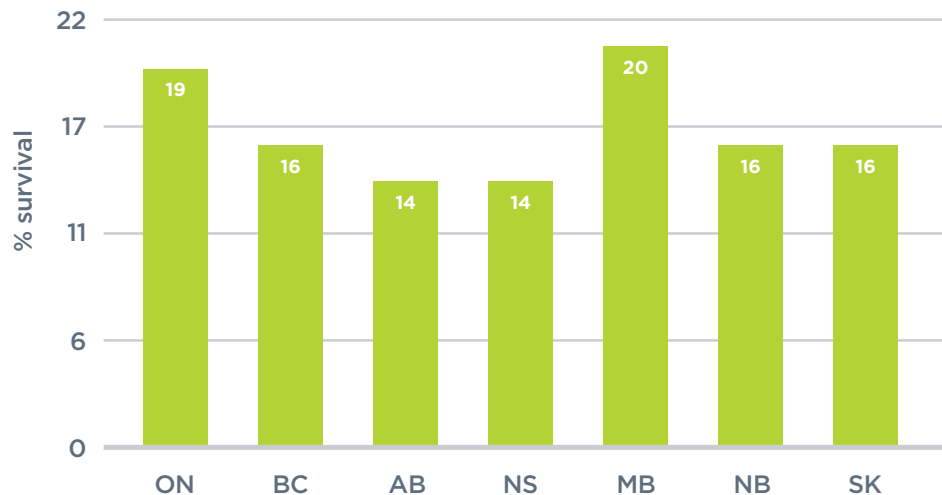
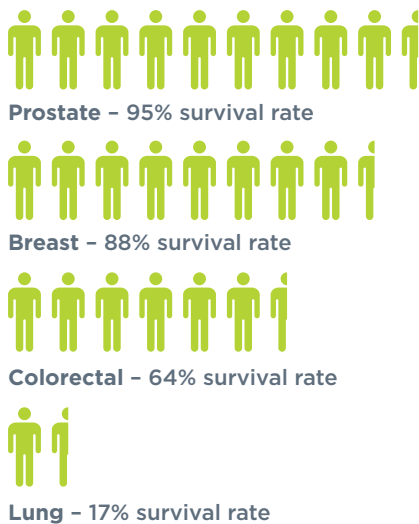
	Canada	BC	AB	SK	MB	ON
Total	20,900	2,500	1,610	580	710	7,100
Male	10,900	1,250	830	290	360	3,700
Female	10,000	1,250	780	290	350	3,400

	QC	NB	NS	PE	NL	
Total	6,500	600	710	110	400	
Male	3,500	340	350	60	230	
Female	3,000	260	360	50	170	

**THIS MUST
CHANGE**

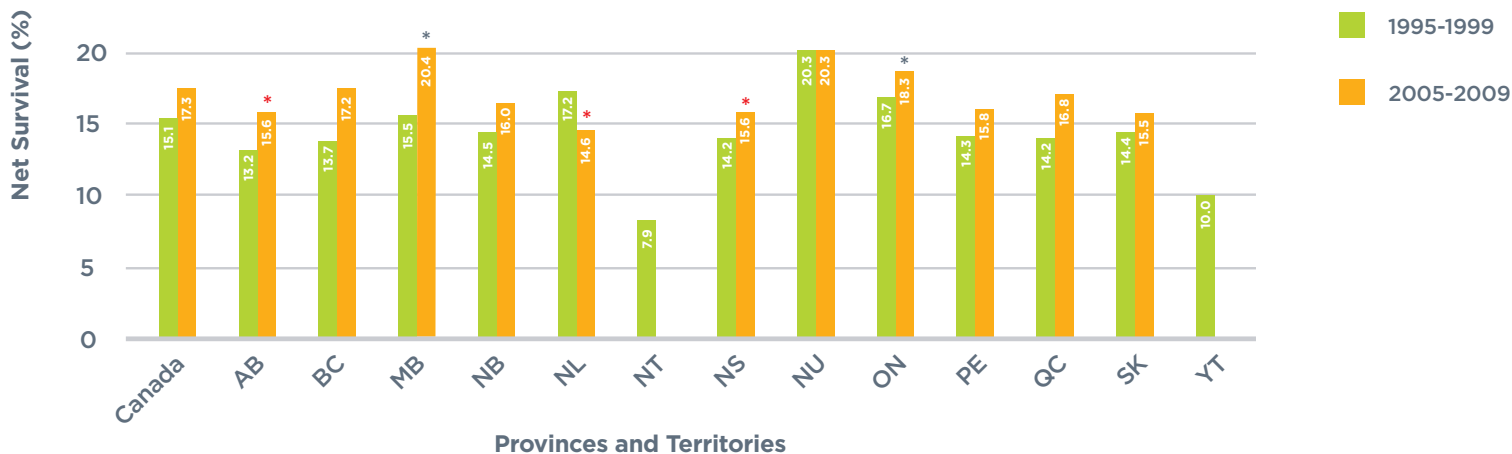
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Five-year survival rates in Canada¹



Source: Canadian Cancer Statistics 2015, p. 67

Five-year survival rates for lung cancer in Canada, 1995-1999 and 2005-2009²



Data Source: CONCORD-2 study supplemental appendix (November 2014)

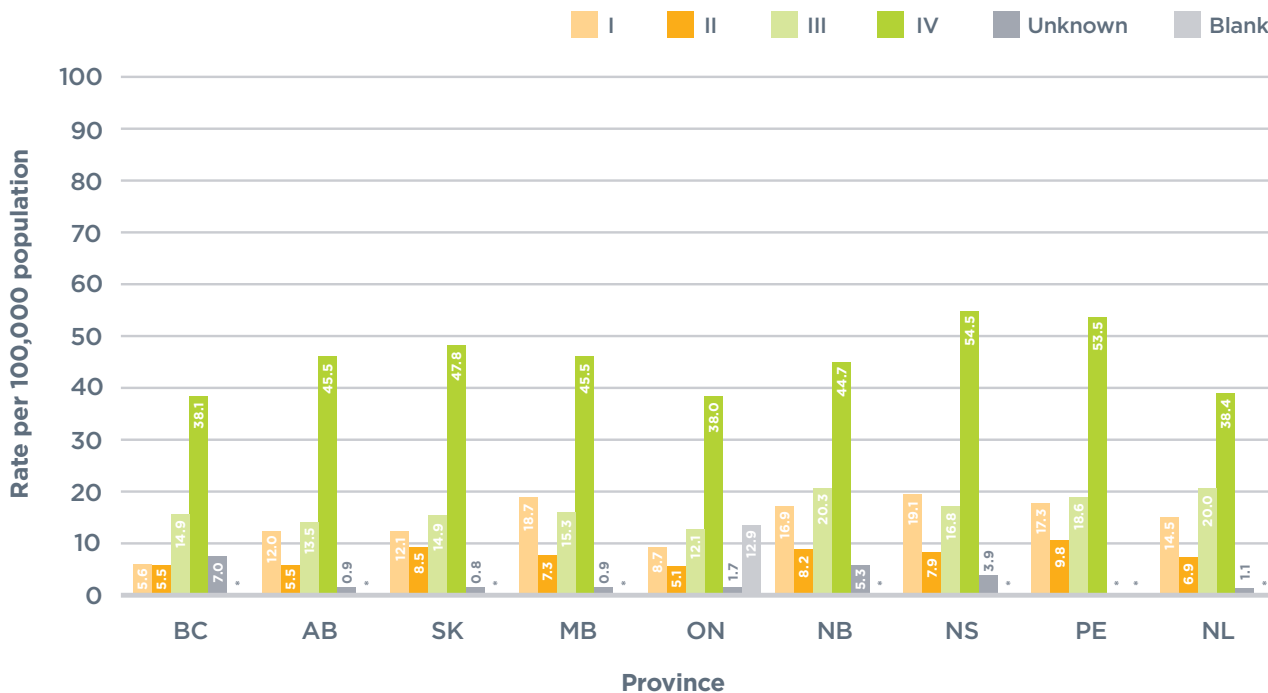
* Statistically above Canada's five-year net survival * Statistically below Canada's five-year net survival

SURVIVORSHIP IN LUNG CANCER IS FURTHER HANDICAPPED BY LATE DIAGNOSIS³

Across Canada, most lung cancers are diagnosed in the most advanced stage of the disease (Stage IV).

- Atlantic provinces have higher rates of advanced-stage lung cancer, which is likely a result of higher smoking rates in these provinces.

Diagnosis of new lung cancer cases by stage of disease and by province



MOST LUNG CANCERS ARE DIAGNOSED IN THE MOST ADVANCED STAGE OF THE DISEASE (STAGE IV).

* Suppressed due to statistical unreliability caused by small numbers. QC stage data for 2010 were not available. Unknown = data entered in the Collaborative Stage algorithm were not sufficient to ascertain a stage. Blank = no staging information was entered into the patient's record. Data source: Statistics Canada, Canadian Cancer Registry.

SMOKING IS ON THE DECLINE – THE MAJORITY OF LUNG CANCER PATIENTS ARE NEVER SMOKERS OR NO LONGER SMOKE

LUNG CANCER CANADA SUPPORTS INCREASING AWARENESS AND CONTINUED LEGISLATION THAT PROTECTS CANADIANS FROM THE HARMFUL EFFECTS OF TOBACCO PRODUCTS. THIS COUPLED WITH CONTINUED INVESTMENT IN SMOKING CESSATION PROGRAMS WILL HELP REDUCE INCIDENCE RATES OF LUNG CANCER.

While tobacco smoking is still the number one cause of lung cancer, fortunately, fewer Canadians are smoking today than a decade ago and smoking rates are declining.^{4,5} Latest data indicate that only **12% of adults aged 55 years or older still smoke.**⁶ Furthermore, Canada's tobacco control continues to evolve and mature.

- The U.S. Surgeons' report released in 1964 was the first to recognize smoking as a cause of lung cancer and is often credited as the turning point in public opinion on the harms of smoking.⁷

- In Canada, smoking bans in public places were only implemented by all provinces and territories by 2008.
- In June 2015, a historic ruling by a Quebec judge ordered three major cigarette companies to pay \$15 billion to smokers in what is believed to be the biggest class-action lawsuit ever seen in Canada.province has adopted a comprehensive lung cancer screening program.

“[There is] no education or compassion on the public’s part that anyone with lungs can get this cancer; that the majority that have it are now non-smokers for years, and/or never smoked...”

– Patient



SCREENING SAVES LIVES AND MONEY

For those that have spent many years under the addictive influence of tobacco, targeted screening programs can help detect lung cancer earlier. Early detection can lead to treatment at an earlier, and more likely curable, stage. As reported in last year's The Faces of Lung Cancer report, lung cancer screening using LDCT (low-dose computed tomography) is an innovation that offers great hope, particularly for those with a high risk of developing lung cancer.⁸

- **Lung cancer screening saves lives:** The National Lung Screening Trial showed that three annual screens using LDCT may reduce lung cancer mortality by 20%.⁹
- **Lung cancer screening can save healthcare resources.** The Pan-Canadian Early Detection of Lung Cancer Study, published in 2014, found that the average cost to screen individuals with LDCT is \$453 per person for the initial 18 months after a baseline scan.¹⁰ If lung cancer is detected at an earlier stage of disease, then patients can be treated with curative surgery, which costs on average \$33,344 per person over two years. These combined costs are significantly lower than the average cost of \$47,792 needed to treat advanced-stage lung cancer with either chemotherapy, radiotherapy, or supportive care alone.

Despite the potential to save Canadian lives and lessen the burden on the healthcare system, to date, **no province has adopted a comprehensive lung cancer screening program.**

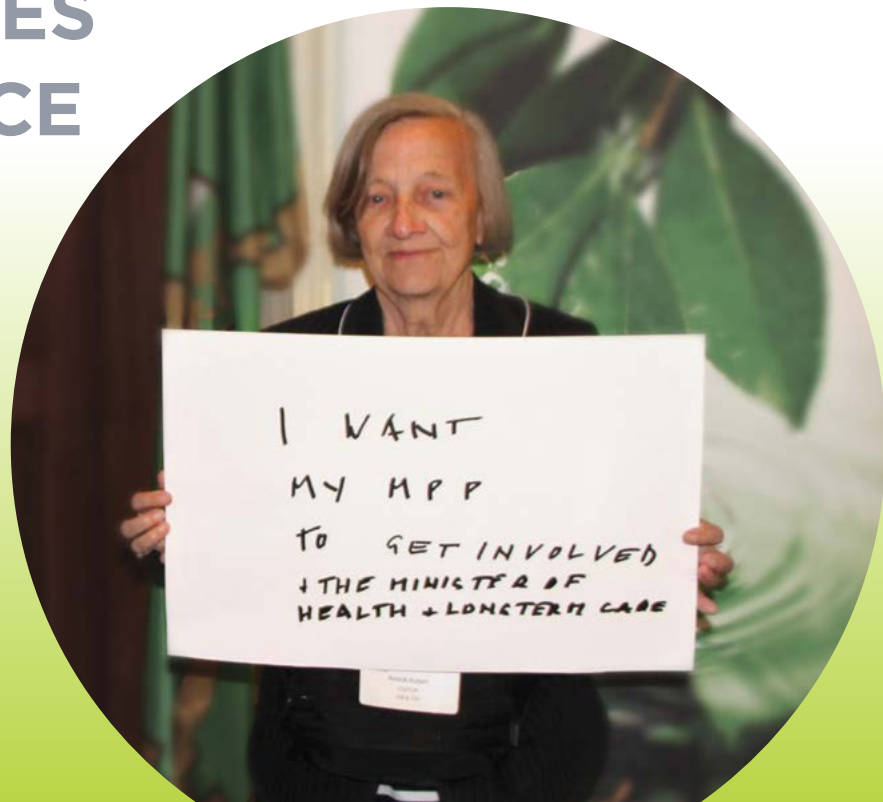


LUNG CANCER CANADA BELIEVES THAT LUNG CANCER SCREENING CAN SAVE LIVES AND LESSEN THE SIGNIFICANT BURDEN ON THE HEALTHCARE SYSTEM. LUNG CANCER CANADA CALLS ON ALL PROVINCES AND TERRITORIES TO ADOPT SCREENING PROGRAMS THAT, AT THE VERY LEAST, TARGET PATIENTS WITH THE HIGHEST RISK OF LUNG CANCER.

PART 2

LUNG CANCER IS A POSTAL CODE DISEASE:

ACCESS TO DIAGNOSTIC TOOLS
AND TREATMENT VARIES
PROVINCE-TO-PROVINCE



ACCESS TO DIAGNOSTIC AND SCREENING TOOLS

Treatment effectiveness and survival increase with early detection and accurate diagnosis of lung cancer. In order to achieve this, patients need to have equal access to diagnostic and screening tools across the country.

DIAGNOSTIC SCREENING

PET (positron emission tomography) is a scanning technique that uses a small amount of a radioactively labelled tracer to look for disease, specifically cancer cells, in the body.¹¹ It allows physicians to determine if a growth in the lungs is cancerous, and decide if the cancer has spread to other areas of the body. An accurate diagnosis or staging of lung cancer with PET also ensures that the most appropriate treatment is given based on the extent of disease involvement.¹² As a result, it has emerged as **one of the most critical first-line tools in the diagnosis of patients with lung cancer**, and it is considered as a standard of care throughout the developed world, where available.



Unfortunately, the number of PET scanners available in each province varies greatly. We currently have two scanners in British Columbia, four in Alberta, one in Manitoba, 12 in Ontario, 16 in Quebec, two in New Brunswick, and one in Nova Scotia.¹³ When population size is taken into account, the disparity in the number of PET scanners between provinces becomes even more apparent, especially in British Columbia, where a diagnosis of 3,150 new lung cancer cases are expected in 2015.

There are also significant differences across Canada in the use of PET scanners for the diagnosis of lung cancer. Amongst Canadian patients with NSCLC, the most common type of lung cancer, the proportion of those who received a PET scan ranged from 17.3% in Manitoba to 37.6% in Ontario between 2009 and 2011.¹³ While PET scans are not required in all cases, the variation in usage seen across the country highly suggests that there is an **underutilization of this resource in many provinces**. For that reason, a greater effort must be put forth so that these numbers are more consistent across the country.

Proportion of patients with NSCLC who received at least one PET scan within three months before or up to one year after diagnosis between 2009 and 2011

BC	AB	MB	ON	NB	NS
27.6%	33.8%	17.3%	37.6%	22.2%	29.3%

IN 2016, LUNG CANCER CANADA, IN CONJUNCTION WITH A PANEL OF EXPERTS, WILL RE-EXAMINE MOLECULAR TESTING IN CANADA AND UPDATE ITS 2014 POLICY ON MOLECULAR TESTING IN CANADA.

MOLECULAR TESTING

The pairing of health technologies with pharmacotherapy is also shifting the paradigm of how we can treat lung cancer. Increasingly, it is becoming more important to understand the molecular subtype of an individual's lung cancer to guide their treatment. Molecular testing looks for biomarkers and other biological targets, and offers patients access to medications that have better response rates and a higher quality of life. We are now in an evolving age of personalized medicine, with healthcare providers concentrating on getting the right treatment to the right person at the right time.

Unfortunately, research and the healthcare system do not always move at the same pace. New drugs that target mutations in lung cancer such as **EGFR** (epidermal growth factor receptor) and **ALK** (anaplastic lymphoma kinase) have been available for many years in Canada. However, **government funding for EGFR and ALK testing has been lagging**, with Ontario only recently funding EGFR testing in 2014.¹⁴ As a result, a recent global survey

indicated that 71% of newly diagnosed Canadian patients with NSCLC are tested for mutation status.¹⁵ Although all provinces currently cover this type of testing, not all centres can conduct the test or have access to a validated lab in their province. For example, Saskatchewan sends their tissue samples to Edmonton for ALK testing. Other issues, such as long turnaround times or problems with the tissue sent for testing, cause some patients to miss out on their chance for targeted treatments.

Mapping the genetic make-up of tumours, which later contributes to the development of personalized medicine, is an ongoing area of research. Though there are currently only two molecular targets in lung cancer that have been approved as treatments in Canada, specifically EGFR and ALK, many others are being actively researched. **Immunotherapies**, or drugs that allow the immune system to attack cancer cells, are a rapidly emerging group of medicines in lung cancer. Since these drugs may also require molecular testing, it is clear that testing should be not only equally available across the country, but also technologies that allow for such testing need to be developed.

Lung Cancer Canada believes that molecular testing will play an increasingly important role in matching patients to better and more tolerable treatments. As part of the standard diagnostic process, it should be readily available to everyone across the country. We call on members from different specialties and industries to work together as partners to discover innovative solutions that will establish a pathway to truly personalized medicine in Canada.

LUNG CANCER WAITS FOR NO ONE

The success of treating lung cancer is dependent on access to treatment centres and healthcare professionals. While the number of specialist centres across Canada is proportional to each province’s population, the number of thoracic surgeons at each centre varies significantly.

- Atlantic provinces are underserved in terms of surgeons per capita, especially compared with Ontario and Quebec.

Number of thoracic surgery centres and surgeons across Canada¹⁶

	BC	AB	SK	MB	ON	QC	NB	NS	NL
Thoracic surgery specialist centres	4	2	1	1	15	5	2	2	0
Number of thoracic surgeons	15	10	5	5	81	27	3	2	2

There is also a substantial **disparity in wait times for surgery and radiation treatment** between provinces.

- Patients can expect to wait anywhere from 14 days in Saskatchewan to 35 days in Alberta.

- After an appointment with a specialist, lung cancer patients have to wait anywhere from one and a half weeks in Saskatchewan to three and a half weeks in New Brunswick to receive radiation treatment.¹⁸

Wait times to date of surgery among lung cancer patients¹⁷

	BC	AB	SK	MB	ON	QC	NB	NS	NL
Median (days)	20	35	14	20	18	22	15	34	22

ACCESS TO TREATMENT: DISCRIMINATION BY POSTAL CODE?

Each Canadian province independently decides whether to reimburse a specific therapy or not. Unfortunately, this results in variations across the country, and where you live can determine your access to treatment.

Provincial reimbursement policies for lung cancer therapies*													
	BC ¹⁹	AB ²⁰	SK ²¹	MB ²²⁻²⁵	ON ^{22,26}	QC ^{27,28}	NB ^{22,29,30}	NS ^{31,32}	NL ^{14,22,33}	PE ^{14,34}	YT ^{14,35}	NT ¹⁴	NU ¹⁴
First-line, second-line, and maintenance pemetrexed	✓	✓	✓	✓	✓	✓	✓	✓	✓	/	/	/	/
Gefitinib for EGFR+ NSCLC	✓	✓	✓	✓	✓	✓	✗	✓	✗	✗	✓	✗	✗
Afatinib for EGFR+ NSCLC	✓	✓	✓	✓	✓	✗	✓	✓	✓	✗	✓	✗	✗
Crizotinib for first-line ALK+ NSCLC	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
Crizotinib for second-line ALK+ NSCLC	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗	✗	✗
Erlotinib for second and third line	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Ceritinib for first-line	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗

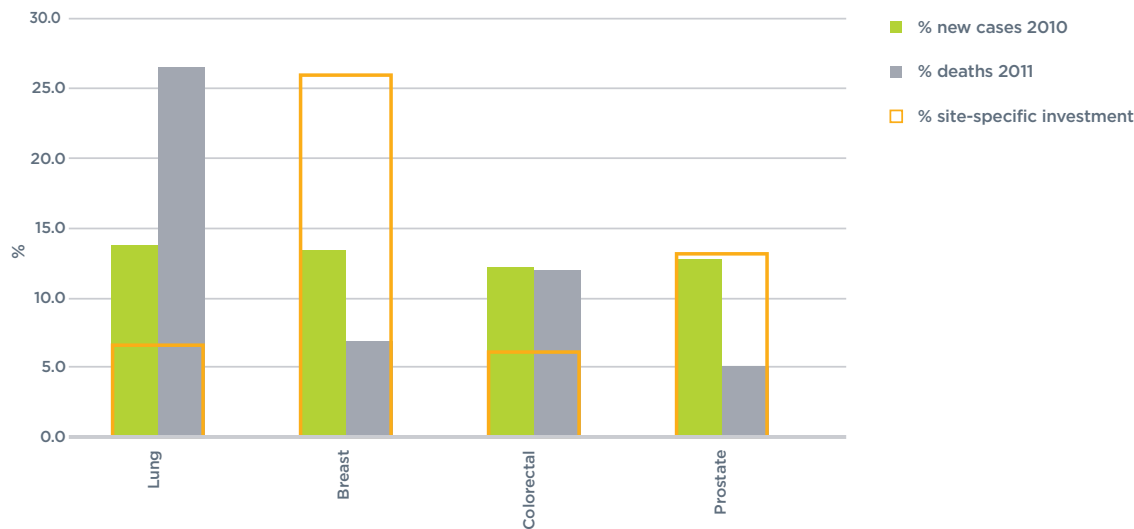
* Coverage as of October 2015. For up-to-date information about the funding status and/or criteria of each medication, please contact your provincial/territorial drug program, cancer agency, and/or Health Canada's Non-Insured Health Benefits (NIHB³⁶) program. Legend: ✓ = covered; / = no data; ✗ = not covered

LUNG CANCER CANADA BELIEVES THAT UNIVERSAL HEALTHCARE SHOULD MEAN EQUALITY ACROSS THE COUNTRY. THAT IS, LUNG CANCER PATIENTS IN BRITISH COLUMBIA OR QUEBEC SHOULD HAVE ACCESS TO THE SAME HEALTHCARE RESOURCES AS LUNG CANCER PATIENTS IN NEW BRUNSWICK, OR PEI. ALL CANADIAN PATIENTS SHOULD HAVE EQUAL ACCESS TO DIAGNOSTICS, TREATMENTS, AND CARE.

RESEARCH INVESTMENT

Although lung cancer has the highest mortality of all cancers in Canada, there is a disproportionate amount of research investment allocated to it compared with other cancers. In fact, as of 2012, significantly more funds were going into research for breast cancer, prostate cancer, and leukemia.³⁷ While it is important that these cancers continue to receive research funding, it is also important to acknowledge the obvious need for more investment in lung cancer research that, at the very least, matches the significant burden of this disease.

Proportion of research investment in Canada for select cancers relative to the distribution of new cases and cancer deaths



LUNG CANCER CANADA BELIEVES THAT RESEARCH INVESTMENT IN LUNG CANCER NEEDS TO REFLECT THE SCOPE AND BURDEN OF THE DISEASE. RESEARCH IS A PROVEN WEAPON IN THE BATTLE AGAINST CANCER. THEREFORE, THE RELATIVELY LOW LEVEL OF FUNDING FOR LUNG CANCER RESEARCH MUST BE ADDRESSED IF WE ARE TO TRULY IMPROVE SURVIVORSHIP.

PART 3

AN AVALANCHE OF VOICES: THE PATIENT AND CAREGIVER SURVEY



The voice of lung cancer is the voice of the patient and their circle of care. Lung Cancer Canada conducted an online survey to:

- **Gain insights** from lung cancer patients and their caregivers
- **Give a voice** to the emotions, challenges, and needs of those that face this disease on a daily basis

This survey explored patient and caregiver experiences with regard to the impact of lung cancer, treatment and supportive therapies received, challenges associated with symptoms and treatments, treatment decision-making, and unmet needs. The results were ‘ear-opening’ and tell an **unheard story of an incomplete circle of care in lung cancer** – one that has a significant impact on both patients and caregivers throughout the cancer journey.

PATIENT AND CAREGIVER PROFILES

A total of **163 people** completed the questionnaire, with **91 patients** and **72 caregivers**.

Survey demographics

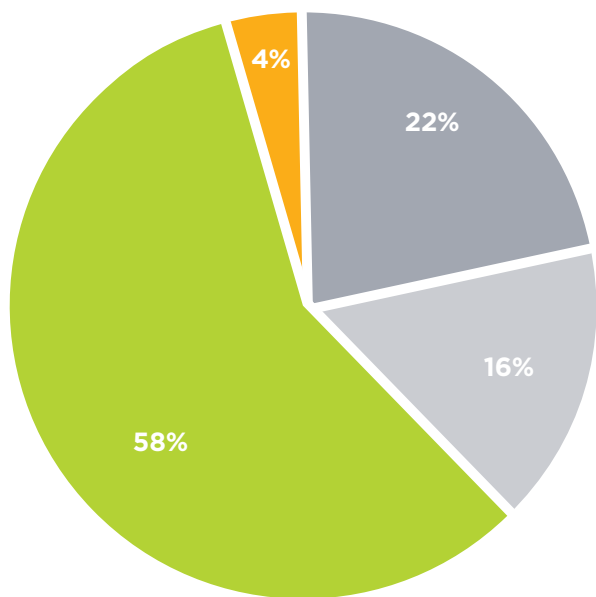
Research method	Primary, quantitative research
Data collection method	Online survey
Language	English and French
Target respondent	Lung cancer patients and caregivers
Screening criteria	- Age: ≥18 years - Patients: current or previous diagnosis of lung cancer - Caregivers: currently caring or previously having cared for someone with lung cancer
Sample size	163 completed interviews (162 in Canada and one in the U.S.) - 91 patients - 72 caregivers
Questionnaire length	15 minutes
Field dates	August 12, 2015 to September 1, 2015

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PATIENTS

- More than half of the patients surveyed (57%) reported that they had no current evidence of cancer.
- Of those with cancer, 22% said that their cancer was localized, and 16% had metastatic cancer (4% were unsure).
- These numbers themselves tell a story about lung cancer. Due to the poor survival rate of this deadly disease, most patient advocates come from the small proportion of survivors. **We must advocate strongly for the majority who no longer have a voice.**

Current condition of the patients surveyed

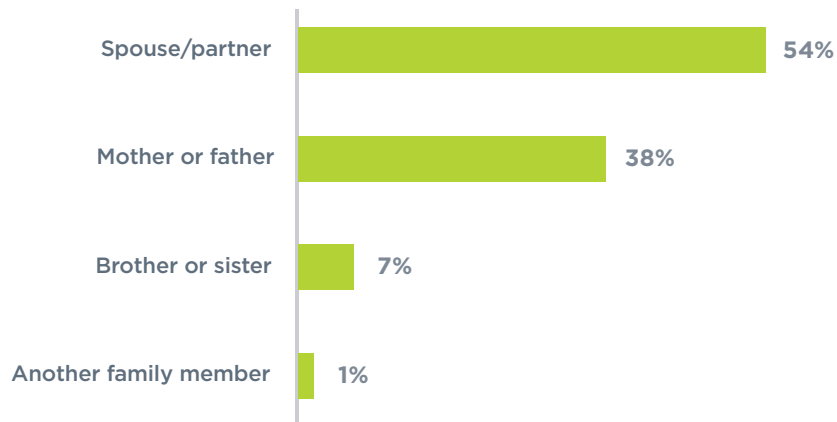


■ Localized ■ No current evidence of cancer
■ Metastasized ■ Not sure

CAREGIVERS

- The majority of caregivers who responded were former caregivers (79%), who stopped providing care because the care receiver either passed away (68%) or recovered (32%).
- Most caregivers (60%) were the primary caregiver and all provided care to a family member.

Relationship of patients to caregivers



LUNG CANCER CARRIES A SIGNIFICANT EMOTIONAL BURDEN ON BOTH PATIENTS AND CAREGIVERS

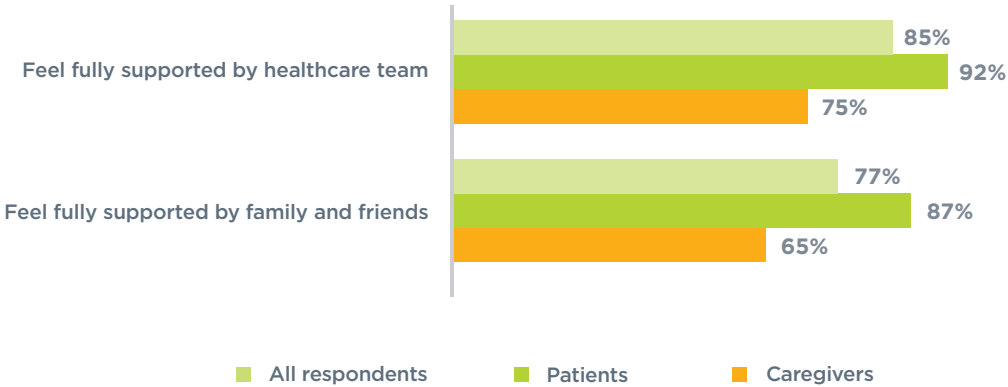
Lung cancer takes a large toll on everyone in its path – not just the patients, but also their loving caregivers. Our survey found that the circle of care for those affected by this disease may be incomplete. Caregivers,

in particular, appear to feel the weight of lung cancer more acutely than the patients themselves, and the hidden emotional burden of this disease needs to be addressed.

SUPPORT

When asked about the support they receive from their healthcare team, family, and friends, the majority of the lung cancer patients felt that they were fully supported, whereas caregivers were less likely than patients to feel this way.

Support from healthcare team, family, and friends



Base: all respondents (n = 163)
Top-two-box percentage (strongly/somewhat agree)
Q20. To what extent do you agree or disagree with each of the following statements about your experience with lung cancer?

STIGMA

The same trend holds with stigma, which is something that has long been associated with lung cancer. This is mainly due to the perception that people have brought the disease upon themselves by smoking. **Although most patients have actually quit smoking by the time they are diagnosed with lung cancer, the stigma still remains.** In fact, recent research has shown that negative implicit or unconscious attitudes toward lung cancer and stereotypes linking smoking with lung cancer were associated with lower rates of drug treatment.³⁸

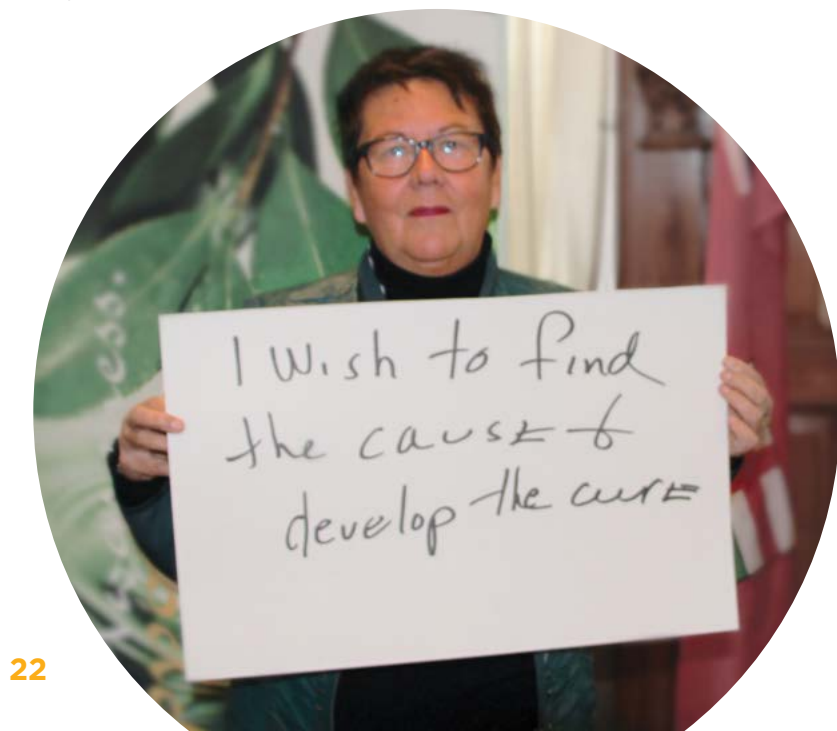
Interestingly, in our survey, it was the caregivers who seemed to experience this particular stigma more than the patients themselves (26% versus 18%). Coupled with the finding that 38% of responding caregivers felt that they had to advocate more strongly for their family members, it is not surprising that they felt more emotionally burdened than patients.

EMOTIONS

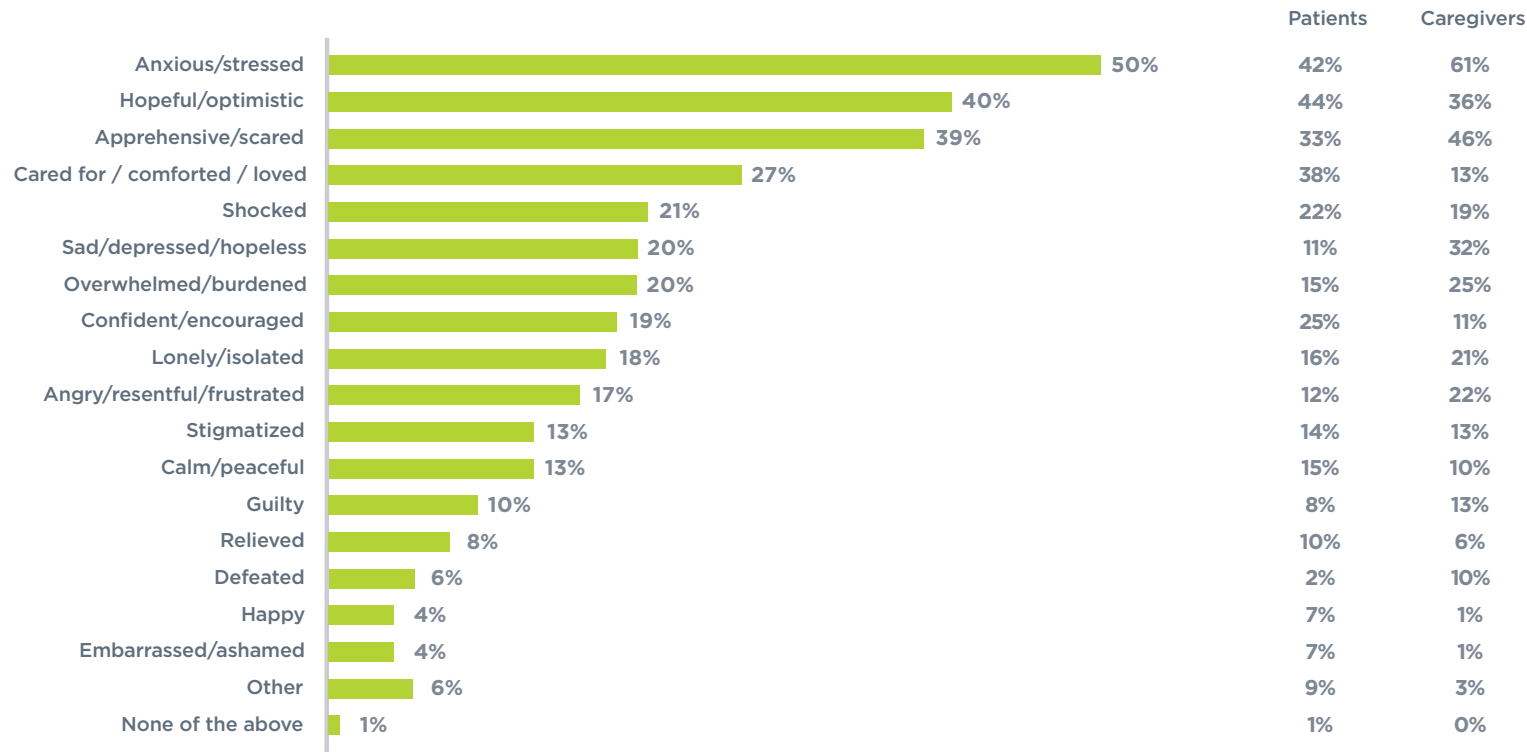
When assessing feelings related to their lung cancer experience, in all cases, **more caregivers felt negative emotions than patients**, whereas more patients expressed positive emotions. For example, 61% of caregivers reported feeling anxious or stressed compared with 42% of patients feeling the same way. Patients expressed hope to a higher degree than caregivers (44% versus 36%), and felt more encouraged and confident (25% versus 11%).

“Everyone assumes that lung cancer is self-inflicted and somehow people who get it deserve their lot. All I heard when people asked if my mom smoked was: “your mother deserves to die.” It is such an ignorant position and a stigma that doesn’t affect any other disease that I can tell, including others with high lifestyle correlations (type II diabetes, heart disease, etc.). It’s frustrating that if my mom had been diagnosed with breast cancer, she would have been considered a hero, but because it was lung cancer, people don’t even want to talk to me about it.”

– Caregiver



Feelings associated with lung cancer experience



Base: all respondents (n = 163)
 Q18. Which of the following emotions and feelings do you most strongly associate with your experience [caring for someone] with lung cancer? Please select up to five responses.

A number of factors may explain why more patients expressed positive feelings than caregivers, including the following:

- The majority of the patients surveyed had no evidence of cancer, whereas most of the caregivers surveyed had loved ones that had passed away.
- Caregivers may also feel the need to take ‘ownership’ for protecting their loved ones, and as a result, bear more of the negative emotions.

- Additionally, the population surveyed may have or have had an earlier stage or more localized disease than the general lung cancer population, and their thoughts and feelings may differ from those with later stage disease.

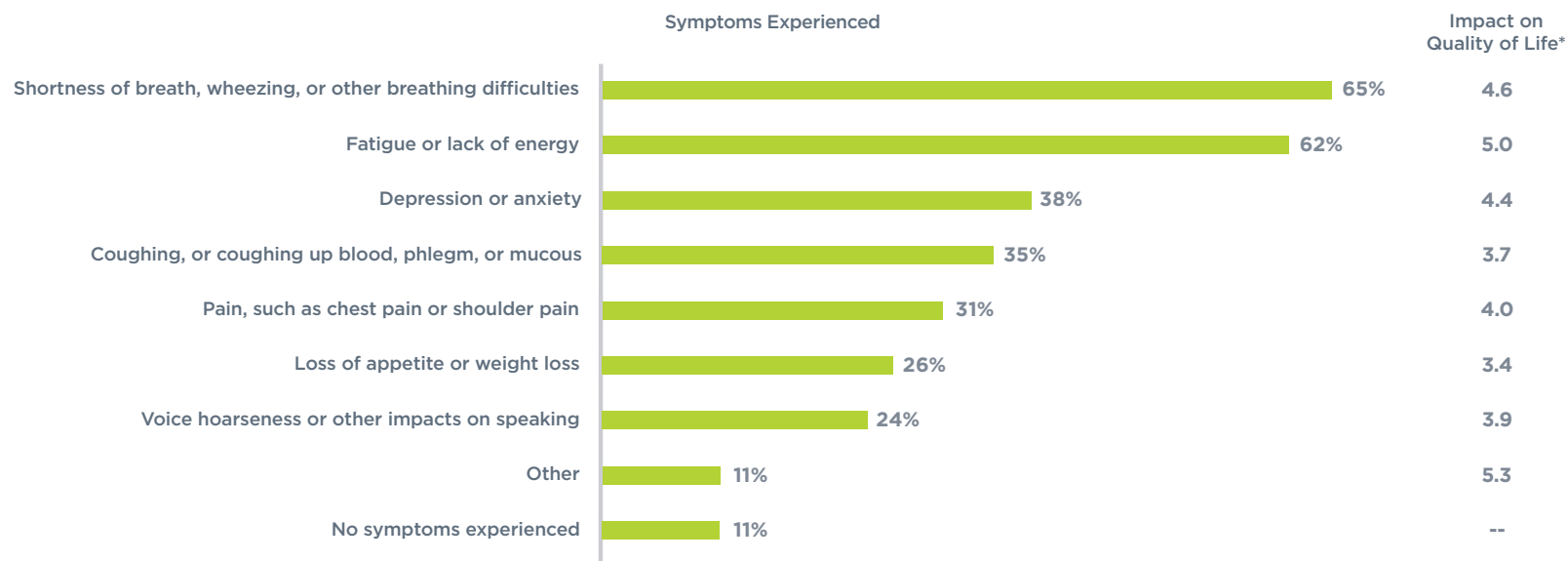
Despite this, it is important to note that less than half of the patients in this survey associated positive feelings with their cancer experience. Even feelings of hope and optimism were only expressed by 44% of patients, and those with late stage disease may have even lower scores.

BOTH PATIENTS AND CAREGIVERS COULD USE A BREATH: SYMPTOMS AND QUALITY OF LIFE

The most common lung cancer symptoms that surveyed patients experienced were **breathing difficulties** (65%), **fatigue** (62%), and **depression or anxiety** (38%). These symptoms are not always fully managed and have the biggest impact on quality of life. Fatigue and lack of energy were also cited by patients (64%) and caregivers (65%) as the most challenging symptoms of lung cancer to manage. Healthcare

professionals agree that these symptoms are the hardest to manage or resolve with traditional therapies. Because a number of factors may be involved and there are currently no comprehensive tools available to identify the root cause(s) of these symptoms, it is difficult to tailor therapies for managing them.

Symptoms and impact on quality of life



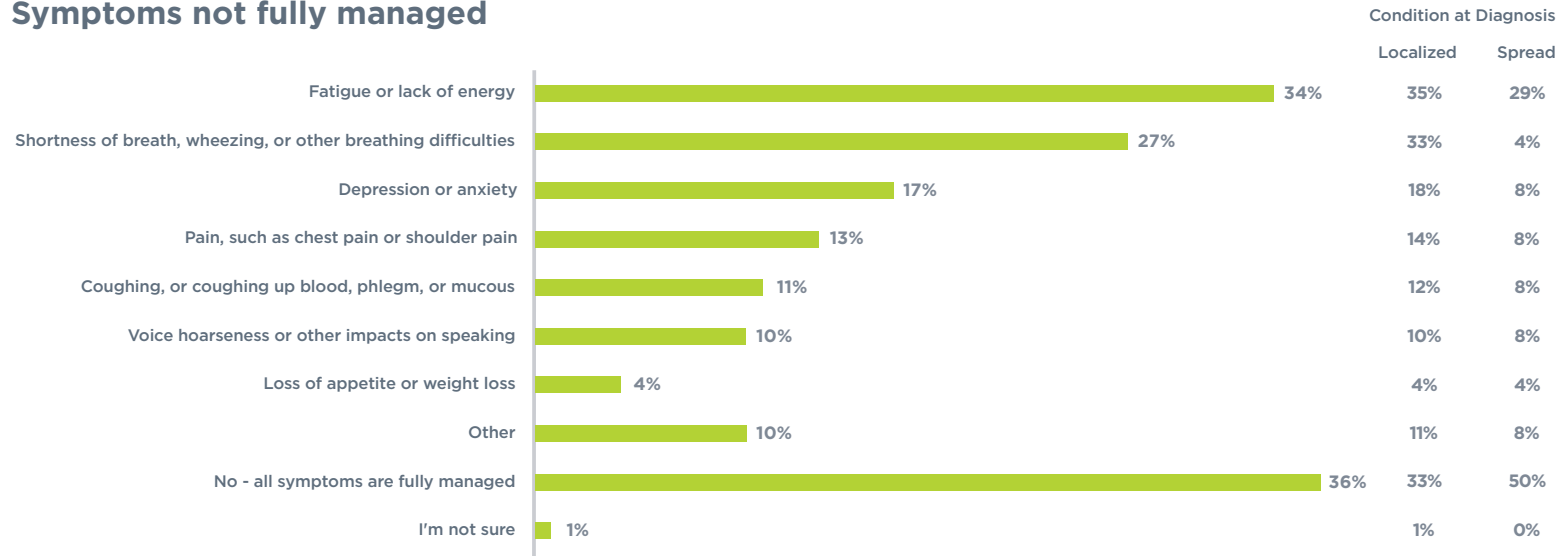
Base: all patients (n = 91)

*Note: mean score out of seven. Impact of quality of life asked only of those patients who experienced symptom.

Q22. Which of the following symptoms have you experienced because of lung cancer? Please select all that apply.

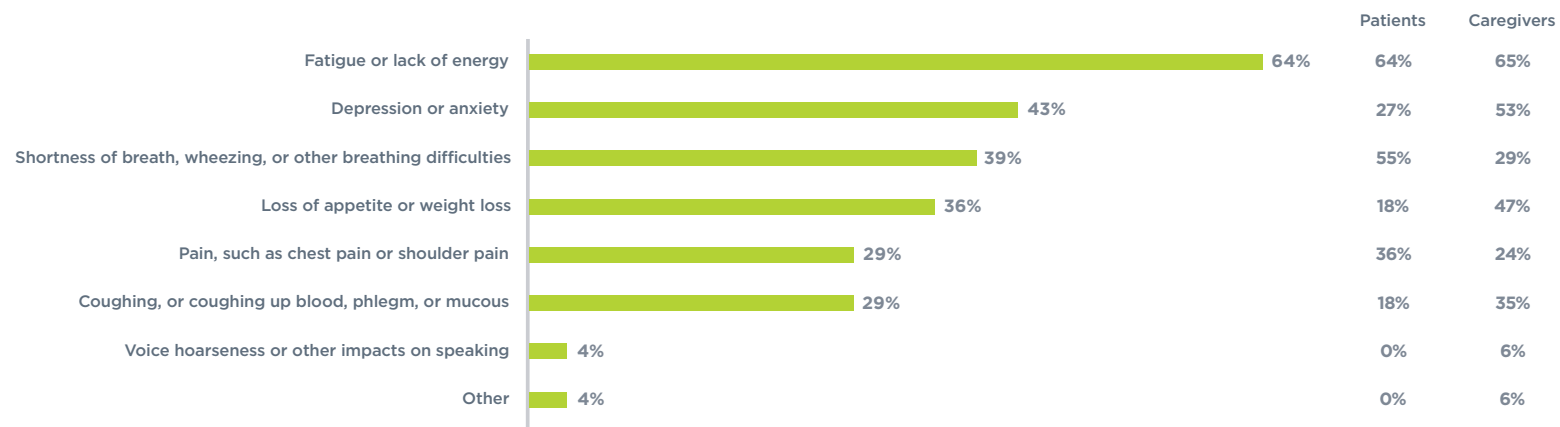
Q23. To what extent have your cancer-related symptoms affected your quality of life? Please rate each of the following symptoms on a scale from 1 (no impact on quality of life) to 7 (extremely large impact on quality of life).

Symptoms not fully managed



Base: received treatment or supportive therapy, excluding caregivers whose care receiver passed away (n = 121)
 Q46. Do you/Does the person you care(d) for have any symptoms that treatments and/or therapies do not address at all, or do not treat as well as you would like?

Most challenging symptoms of lung cancer



Base: managing symptoms selected as difficult aspect of treatment (n = 28)
 Q42. Which of the following symptoms of lung cancer have been most challenging for you to manage [as a caregiver]?

THE FACES OF LUNG CANCER REPORT

Patients were not the only ones struggling to “catch their breath” — **caregiving impacts all aspects of life**. Only 36% of caregivers felt that their overall quality of life was either excellent or very good. About eight out of ten caregivers (82%) also said that their caregiving experience was very to somewhat stressful. The most common sources of stress for caregivers were **dealing with the care receiver’s declining health**

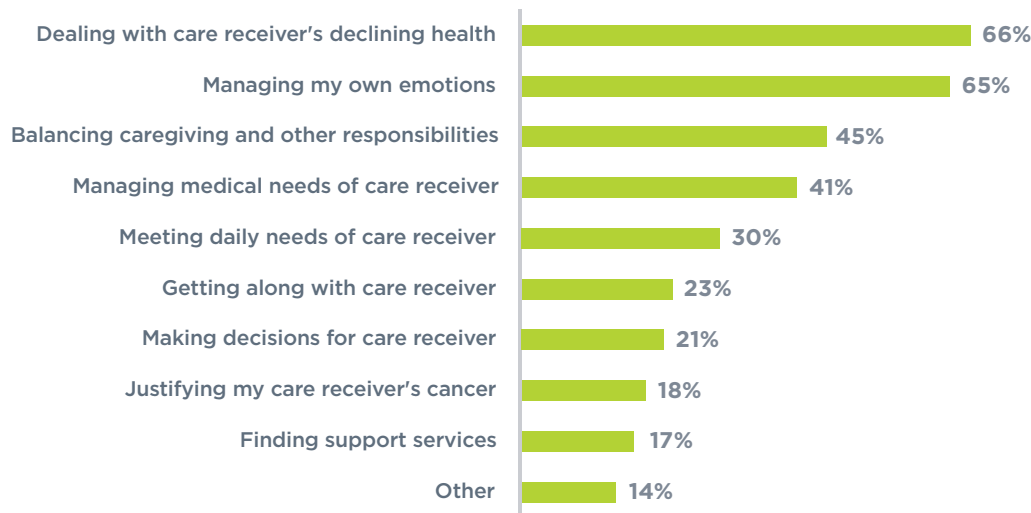
(66%) and **managing their own emotions** (63%). The day-to-day aspects of caring for someone with lung cancer, such as managing the medical needs of their loved one, meeting their daily needs, and even simply getting along with them were also significant stress factors.

Stress associated with caregiving responsibilities

Extent of Stress



Specific Stressors

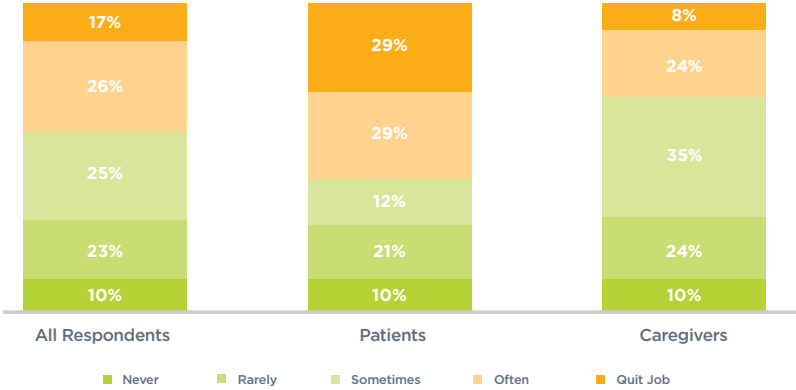


Base: all caregivers (n = 72); Q31 asked of caregivers who experienced at least some stress (n = 71)
Q30. Overall, how stressful is/was your caregiving experience?
Q31. What specifically has been stressful about your caregiving experience?

Work and relationships often gave way to the challenge of providing care. Over half of caregivers (59%) reduced the number of hours they worked, and a further 8% quit their jobs. Not surprisingly, 50% of caregivers reported a negative impact on their household financial

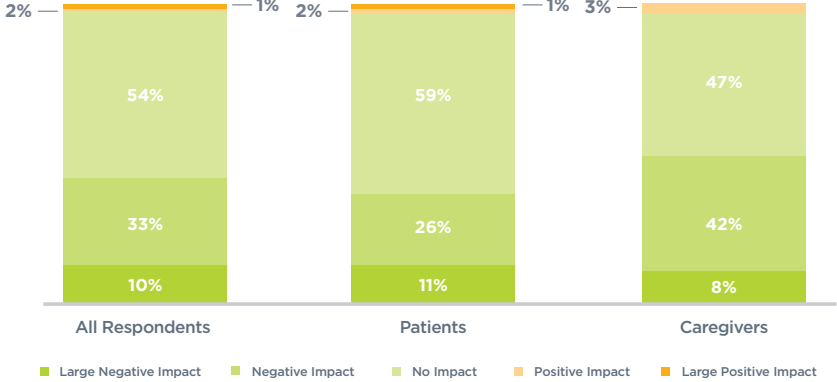
situation. With patients understandably reducing their number of working hours or being unable to continue with work, this trend threatens to have a significant impact on the economy by taking not one, but often two members out of the workforce for every lung cancer case diagnosed.

Frequency of reducing hours worked



Base: patients and caregivers working full- or part-time at time of diagnosis (n = 93; 42 patients and 51 caregivers) Q25. How often, if at all, have you had to reduce the number of hours you work(ed) because of your illness / your responsibilities as a caregiver?

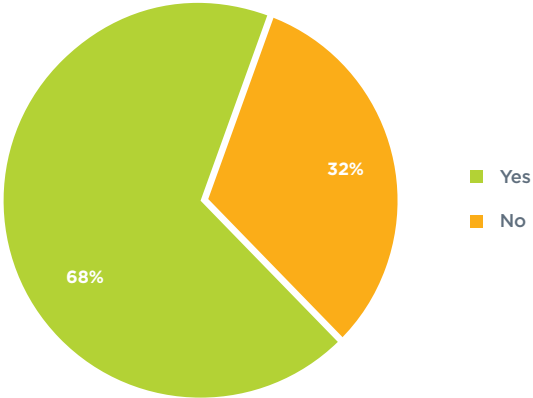
Impact on household financial situation



Base: all respondents (n = 163) Q28. What impact, if any, has your experience with lung cancer had on your household financial situation?

Strain or conflict in relationships due to caregiving

Among the 32% of caregivers who have experienced strained relationships or conflict with family or friends, **lack of compassion** and **support** were the primary causes.



Base: all caregivers (n = 72); Q31 asked of caregivers who experienced at least some stress (n = 71) Q30. Overall, how stressful is/was your caregiving experience? Q31. What specifically has been stressful about your caregiving experience?

“While some of my friends are supportive, others just **ignore what I’m going through and never ask about how we are doing** (even though I see them regularly). I’m not sure if this reflects their own discomfort with what we’re going through or if they just don’t understand how serious our situation really is, but either way I find it hurtful.”

“One sibling was the main caregiver as she lives in the same town as my parents. The other two were only an hour away and rarely if ever helped. I traveled 8 hours to help every month or two. Near the end I was there more than I was home. It was a constant battle to get the others to go visit my parents. **The decisions and the lack of involvement really strained our relationships.**”

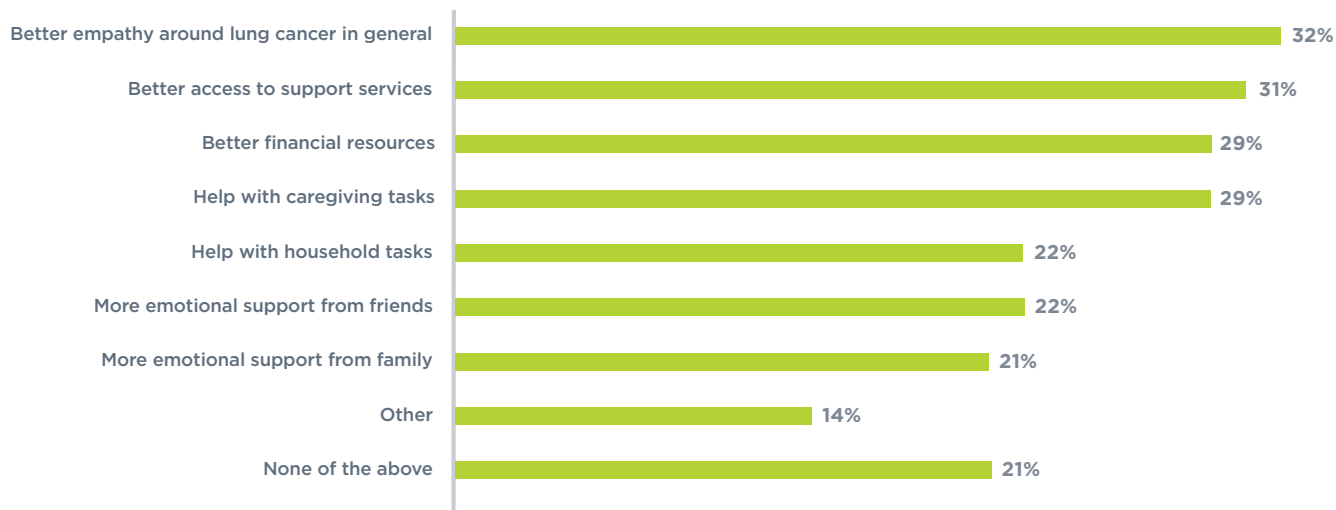
“**Friends did not understand the severity of the situation and just didn’t understand the support I had to give my family, rather than doing social activities.**”

‘IVE CARE: PUTTING THE SUPPORT INTO CARE

When asked what would make caregiving easier to manage, the top two answers point to stigma and support: caregivers most often mention **greater empathy towards lung cancer in general** (32%) and **better access to support services** (31%). **Better financial resources** (29%) and **help with caregiving tasks** (29%) also ranked highly.

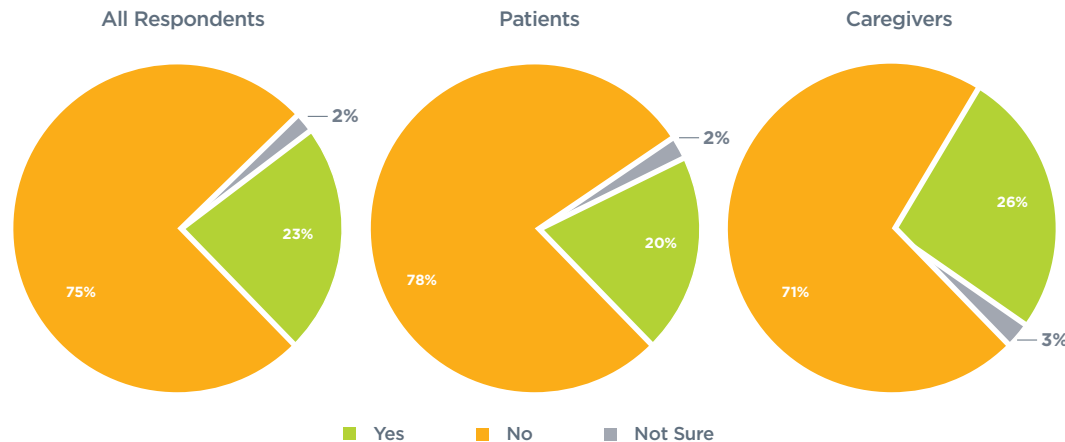
Although **social work** and **counselling** can play a key role in helping to manage cancer, only 20% of patients and 26% of caregivers have ever received such healthcare support services. Even when these services are offered, wait times and access points can differ between provinces, regions, and cities.

Support that would make caregiving easier to manage



Lung Cancer Canada believes that quality of life for patients also includes quality of life for caregivers. We believe that there is a need to engage additional psychosocial supports for both patients and caregivers, as it affects all aspects of the lung cancer journey. Supportive services need to include care and treatments for more than just the tumour; these include expanding access to palliative services and engaging nurses to navigate and provide support services. Currently, caregivers make a significant amount of personal sacrifice that has health, social, and economic implications.

Ever received social work or psychological counselling



“Sometimes it is very difficult to ask for help—at times I don’t know how someone can help, and at others, I’m ashamed to have others feel that I am not coping well. My doctor suggested I keep a list of practical things such as a meal, a ride, or a couple of hours by myself that people can do for me. It helps with the load and keeps me from feeling overwhelmed.” – Caregiver

Expanded access to palliative care can also help provide support. Palliative care can help with a holistic approach to symptom management and support systems for both patients and caregivers. However, at times, the term ‘palliative care’ is misunderstood. There is a perception that palliative care is only for those that are imminently dying and is intended for maintaining comfort in the last days of life.³⁹ In fact, the opposite may be true. A study conducted in Boston amongst patients with metastatic NSCLC suggested that early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients that received early palliative care had less aggressive care at the end of life, and surprisingly, significantly longer survival.⁴⁰ This points to an idea that ‘care’ is just as important as ‘treatment’. Indeed, early access to palliative care was found to directly address the negative factors affecting quality of life – the very same factors that were also identified in this survey.

LUNG CANCER CANADA’S FACE-TO-FACE PEER NETWORK CONNECTS LUNG CANCER PATIENTS AND THEIR CAREGIVERS WITH PEERS WHO HAVE EXPERIENCED THE LUNG CANCER JOURNEY. THE GOAL OF THIS PEER-TO-PEER NETWORK IS TO PROVIDE SUPPORT AND SHARE INSIGHTS AND EXPERIENCES SO THAT EVERYONE’S VOICE IS HEARD. TO BECOME A PEER SUPPORTER OR RECEIVE PEER SUPPORT SERVICES, PLEASE EMAIL INFO@LUNGCANCERCANADA.CA.

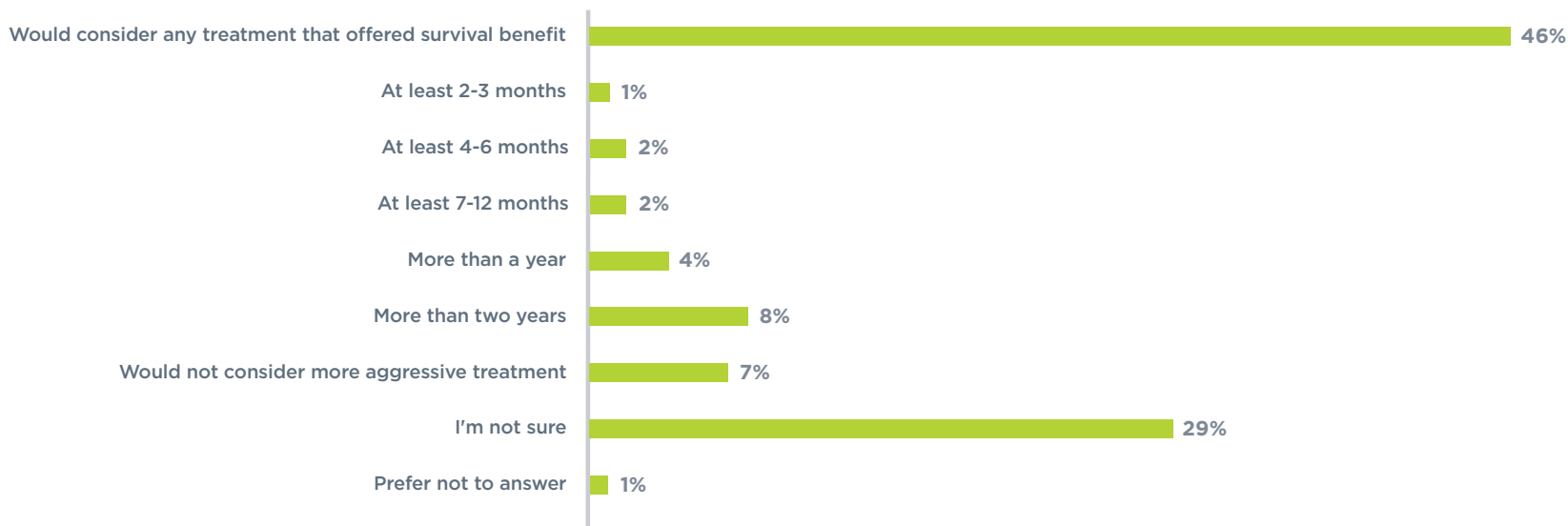
THERE IS A ME THE MIDDLE OF TREATMENT

While physicians make treatment decisions based on **objective clinical evaluation and evidence**, not surprisingly, patients make decisions based on **emotional factors**.

When making decisions about treatment, patients rated **factors related to survival** as the most important considerations (i.e., how long treatment could possibly prolong life and whether treatment is expected to shrink or delay the growth of the tumour). **Symptom relief**

is also important, followed by **side effects** and **how the treatment is administered**. Close to half of respondents (46%) would consider any treatment that offered a survival benefit. Only 7% of respondents say they will not accept more aggressive treatment. At the same time, about one-third of respondents (29%) are not sure what survival benefit would need to occur before they accept more aggressive treatment.

Survival benefit needed before considering more aggressive treatment

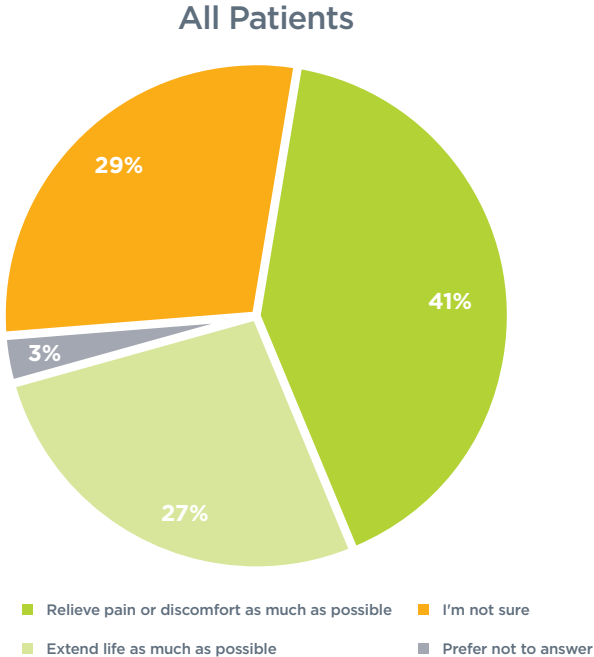


Base: all patients (n = 91) and current caregivers involved in decision making (n = 10)
Q54. What overall survival benefit would need to occur before you would consider more aggressive treatment [for the person you care for]?

This uncertainty is also evident when patients are directly asked to choose between treatment that **extends life as much as possible** – even if it means additional side effects – and **relieving pain or discomfort**. One-third of patients (32%) are not sure or prefer not to answer, while 41% want to relieve pain or discomfort as much as possible and 27% want to extend life as much possible. When framed as

a choice between treatment that extends life as much possible – again, even if it means additional side effects – and relieving pain or discomfort, patients generally prioritize relief of pain or discomfort. However, patients with metastatic cancer are equally split between relieving pain or discomfort and extending life.

Treatment decisions: Relieving pain vs. extending life



	Current Condition		
	No Evidence of Cancer (n = 52)	Localized* (n = 20)	Spread* (n = 15)
Relieve pain or discomfort as much as possible	42%	35%	47%
Extend life as much as possible	25%	20%	47%
I'm not sure	31%	45%	0%
Prefer not to answer	2%	0%	7%

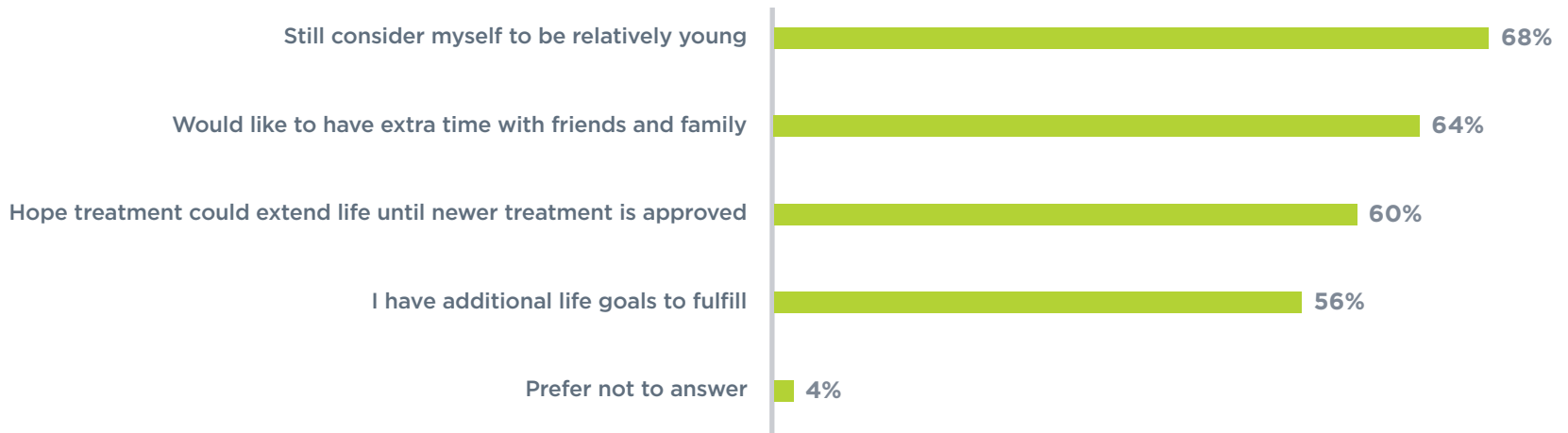
Base: all patients (n = 91)
 *Caution: small base size
 Q55. Would you prefer treatment that extends life as much as possible, even if it means additional side effects, or would you want treatment that focuses on relieving pain and discomfort as much as possible, even if it means not living as long?

THE FACES OF LUNG CANCER REPORT

Among patients who want to extend life as much as possible, their primary reasons for accepting additional treatment – and tolerating additional side effects – are that they still **consider themselves to be relatively young** (68%) and they **desire to spend more time with family and friends** (64%).

It is also important to note that caregivers play a role in treatment decisions. Of the surveyed caregivers, 64% participated in making treatment decisions and another 3% were the primary decision-maker.

Reasons for accepting additional treatment to extend life



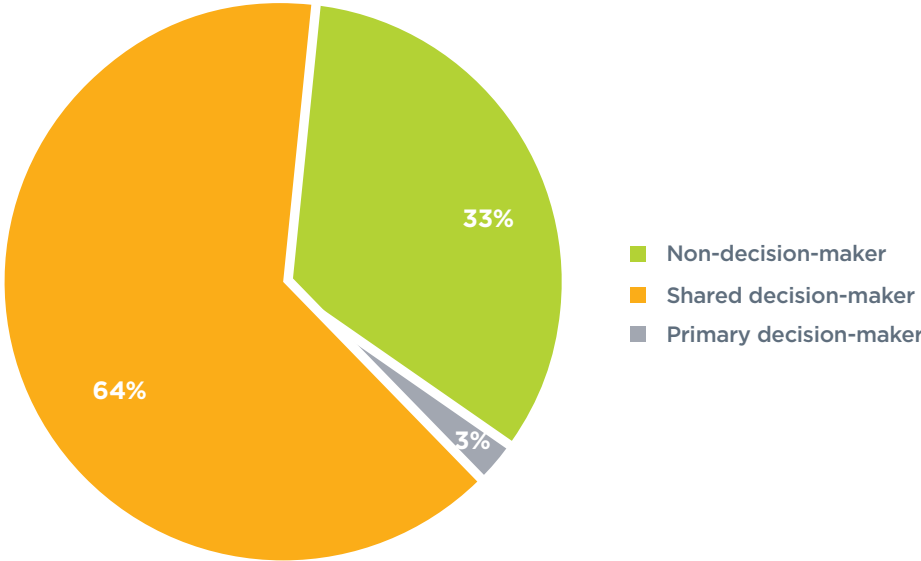
Base: patients who want to extend life as much as possible (n = 25)

Q56. Which of the following best explains why you would accept additional treatment to extend your life as much as possible, even if it meant managing additional side effects?

Understandably, treatment decisions can be very personal, and at times, the physician’s clinical judgement may conflict with patient and caregiver beliefs. It is therefore important for physicians to remember that non-clinical factors play a role when patients are considering treatment. Many physicians will try to get a clear understanding of the patient’s goals, and then try to tailor a treatment plan that matches their aspirations.

Patients and their families wish to be active participants in their decision-making. Among cancer patients, **those offered choices in their treatment show better psychological adjustment and health-related quality of life**, while those feeling that they have had little control over their disease and treatment have a poorer psychosocial outcome.^{41,42} Treatment decision aids can be possible tools that can help improve patient understanding of prognosis, treatment options, risks, and benefits without increasing anxiety.⁴³

Caregivers’ participation in decision-making



Base: all caregivers (n = 72). Q51. As a caregiver, how involved, if at all, are/were you in treatment decisions?

“My 83-year-old mom was diagnosed with NSCLC. Four weeks later, we met with the oncologist who told us she would not consider chemo at this time. Mom is still relatively healthy, but the lung biopsy took a lot out of her and she developed a slight pneumothorax. However, two weeks later, she has improved and feels pretty good. The doctors are making her sound worse than she feels. They said they may consider chemo later on, but I am afraid that it will be too late! I feel like they are moving slowly because of her age!”

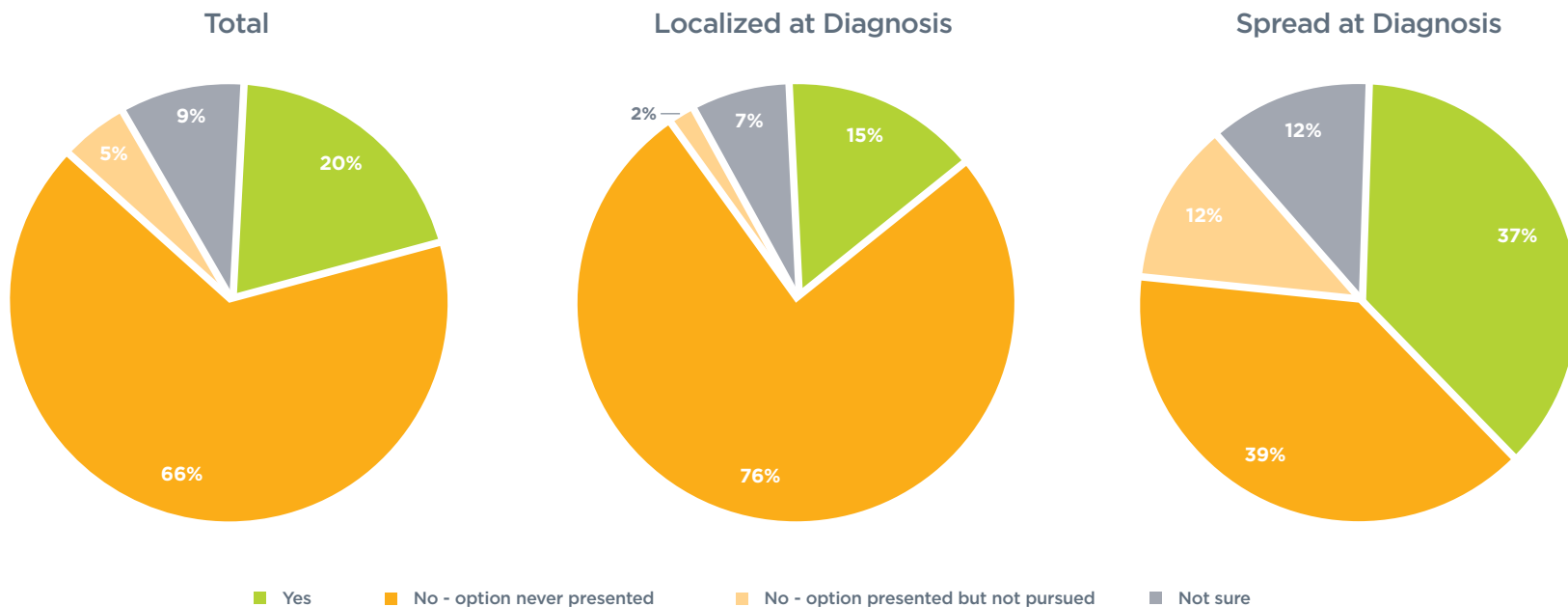
– Caregiver

CLINICAL TRIALS: AN UNDERUSED STANDARD OF CARE?

Participation in clinical trials was found to be correlated with a patient's condition at diagnosis. Patients whose cancer had spread to other parts of the body were unsurprisingly more likely to enrol in clinical trials than those with localized lung cancer (37% versus 15%). This is likely

because there are more clinical trials available for patients with metastatic disease. Unfortunately, a significant proportion of patients were never presented with clinical trials as a treatment option, while only a small percentage rejected the clinical trials when presented with the option.

Participation in clinical trials



Base: received treatment (n = 156); condition at diagnosis: localized (n = 109), spread (n = 41), 'not sure' not shown. Q38. Did you/the person you care(d) for receive lung cancer treatment as part of a clinical trial?

Participation in clinical trials appeared to be positively correlated with household income. **Patients with a household income of over \$100,000 per year were almost twice as likely to participate in clinical trials as**

those with an income of less than \$100,000 per year. Similarly, lower household income was associated with a lower likelihood of the patient being presented with clinical trial participation as an option.

Participation in clinical trials

	Total (n = 156)	Region				Household Income		
		West (n = 50)	Ontario (n = 87)	Quebec* (n = 13)	Atlantic* (n = 5)	<\$50K (n = 42)	\$50K - <\$100K (n = 42)	\$100K+ (n = 42)
Yes	20%	8%	28%	8%	20%	12%	14%	26%
No – option never presented	66%	70%	61%	85%	80%	81%	64%	62%
No – option presented but not pursued	5%	8%	3%	8%	0%	0%	5%	7%
Not sure	9%	14%	8%	0%	0%	7%	17%	5%

Base: received treatment (n = 156). *Caution: small base size. Q38. Did you/the person you care(d) for receive lung cancer treatment as part of a clinical trial?

Participation in clinical trials appears to also vary across Canada.

Patients in Ontario were more likely to be enrolled in clinical trials than patients from other regions, and patients in Quebec were more likely to have never been presented with the clinical trial option after their diagnosis.

Socioeconomic status and regional systems may help explain some of these findings. Wealthier patients may be more educated and be better

informed and equipped to evaluate clinical trials. Secondly, proximity to major cancer centres could play a major role. People with lower incomes may not be able to support the added costs of travelling, which may or may not be reimbursed. Given that low socioeconomic status has been linked to lung cancer, greater effort is required to ensure that everyone has equal access to new, cutting-edge therapies through clinical trials.⁴⁴

Lung Cancer Canada believes that clinical trials should be a standard of care and that all patients should be offered a clinical trial as an option, where available. Regional and socioeconomic status can be significant factors influencing trial participation. Lung Cancer Canada recommends examining trial reimbursement and rollout strategies to allow smaller centres to participate. Patients' access to clinical trials must be facilitated, especially in cases when travel and time off work take a significant financial toll. Patient-centric trial education materials should be developed to help patients and caregivers understand the risks and benefits of trial participation.

PART 4

COMPLETING THE CIRCLE OF CARE



A LUNG CANCER DIAGNOSIS INITIATES AN AVALANCHE OF EMOTIONS, DECISIONS, AND ADJUSTMENTS FOR BOTH THE PATIENT AND THE CAREGIVER.

These are the facts. Survivorship in lung cancer is still not common. Access to treatments can depend on the province and the region where you live.

There is still too much hope for lung cancer. New treatments, such as immunotherapies and targeted therapies, are being developed and offer real hope. As one patient on a new treatment said:

“The hope I was trying to portray was right in front of me. I went from crying every night in the shower so my boys would not hear me, to ‘It’s going to be okay’. **Hope went from just something I said to becoming real.** My older child is 13. I’m determined to meet my grandchildren.”

– Patient

Perhaps one of the first ways by which patients can gain access to new treatments is through clinical trials. Strategies that help patients and their families increase their understanding about clinical trials and how to enrol in them can help more patients gain access to new, cutting-edge therapies.

This report strives to give a voice to a key but often unheard player in a patient’s lung cancer journey – the caregiver. Caregivers play a critical role in navigating the day-to-day struggles of living with lung

cancer. Caring for a loved one affects a caregiver’s own mental, physical, and economic health.

Patient-centric care must include caregivers in order to complete the circle of care. Expanded access to palliative services, nurse navigators, and other supportive services can all help place quality into the life of both the patient and the caregiver – allowing patients and their families to both live and hope.

CONCLUSION

Lung cancer is one of the most common cancers, and of all cancers, is the leading killer in Canada. Yet, on account of underfunding of research, stigmatization, regional differences in access to healthcare resources, and the sheer burden of lung cancer, patients and their caregivers face a number of significant challenges, as outlined in this report.

Lung Cancer Canada is Canada's only national organization focused exclusively on lung cancer. **Lung Cancer Canada urges all stakeholders to step up and advocate for everyone who is affected by this disease.**



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This report was made possible through the generous support of AstraZeneca Canada, Boehringer Ingelheim Canada, Bristol-Myers Squibb Canada, EMD Serono, Pfizer Oncology, Sage Medica, Novartis Canada and Titan Creative. Without your help, this project and endeavour would not have been possible. THANK YOU!

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