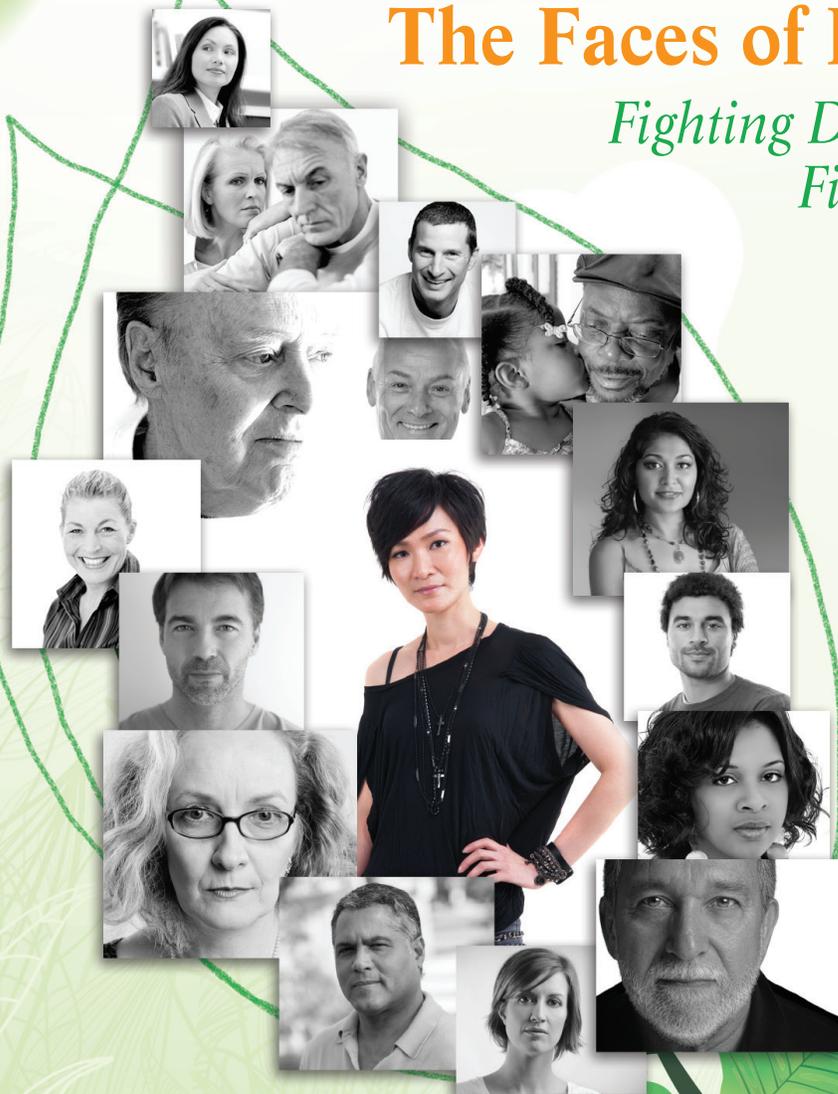


LUNG CANCER CANADA

Awareness. Support. Education.

The Faces of Lung Cancer

*Fighting Disease,
Fighting Disparity*



ACKNOWLEDGMENTS

This report was prepared and designed to highlight the national voices and faces of patients and families living with lung cancer. This endeavour would not have been possible without listening to YOUR voices – THANK YOU. A special thank you is extended to:

Anne Marie Cerato (Toronto, ON) who gave voice to the younger face of lung cancer.

Frances Cerato, Anne Marie's mother whose story of living with both a husband and daughter with lung cancer highlights the impact of lung cancer on families.

Patrick Bardos, Anne Marie's fiancé, who met Anne Marie after she was diagnosed and represents the hope for dreams and futures that everyone living with lung cancer deserves.

Natalie Deschamps (Ottawa, ON) whose voice and strength represent the enormous role of the caregiver in a person's lung cancer journey. Mark is lucky to have you in his corner.

Mary Anne Phillipone (Victoria, BC) whose determination to make a difference and speak represents the importance of the patient's voice. People living with lung cancer must and deserve to be heard.

Jessica Miller (Montreal, QC) who is proof that lung cancer does not discriminate – if you have lungs you can get lung cancer.

Col. Dr Jacques Ricard (Ottawa, ON) whose story speaks to the importance of timely diagnosis and access to treatment. Sometimes days really do make a difference. Thank you for serving our country. May this report and the healthcare system now serve you.

Ruth Wasylenko (Edmonton, AB) whose voice reminds us of the hope offered by clinical trials.

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Dr Silvana Spadafora, Medical Oncologist (Sault Ste Marie, ON)

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Lung Cancer Canada is a national charitable organization that serves as a leading resource for lung cancer education, patient support and advocacy. Lung Cancer Canada is a member of the Global Lung Cancer Coalition and is the only organization in Canada focused exclusively on lung cancer.



...a fight for hope...





The Faces of Lung Cancer *Fighting Disease, Fighting Disparity*

A diagnosis of lung cancer starts a fight – a fight for hope against a disease that too often takes a terrible toll. For most Canadians with lung cancer, it also involves a fight against another enemy – disparity.

While our Canadian health system prides itself on its equality and universality, those concepts only go so far. More than Canadians with other cancers or illnesses, those with lung cancer face the challenges of disparity even more deeply on five important levels that are examined in this report:

- **STIGMA**
- **TOLL**
- **DIAGNOSIS**
- **TREATMENT**
- **RESEARCH**



More needs to be done in Canada to ensure every person diagnosed with lung cancer – our country's most common and deadliest cancer – and their families have the greatest possible opportunity to overcome these disparities and thus open the door to hope.

Lung cancer isn't a disease of individuals. When it strikes one person, it strikes a whole family. Fighting this disease involves more than just one individual – it involves a whole team of dedicated health professionals. And to find the cure for lung cancer involves large teams of researchers and enough funding.

There are many different faces of lung cancer in Canada. Each provides a different perspective on this highly complex and devastating disease. More importantly, they all share one objective – to gain hope that they can win the fight against lung cancer.

DISPARITY #1: STIGMA – NO ONE DESERVES LUNG CANCER

Unique among cancers, lung cancer brings with it a heavy stigma – that people brought the disease on themselves by smoking. A 2010 national poll showed more than one in five Canadians (22%) said they feel less sympathy for people with lung cancer than those with other cancers because of its link to smoking.¹

THE REALITY: **One in 12 Canadian men** and **one in 14 Canadian women** will be diagnosed with lung cancer.² Of those diagnosed, 15% are lifelong *non-smokers*, while 35% more are ex-smokers, who in many cases quit years before their diagnosis. For reasons that are not clear, non-smoking women are significantly more likely to be diagnosed with lung cancer than non-smoking men.



The association of lung cancer with smoking often results in negative reactions and blame from others, assuming those patients “brought it upon themselves”. However, we must remember that:

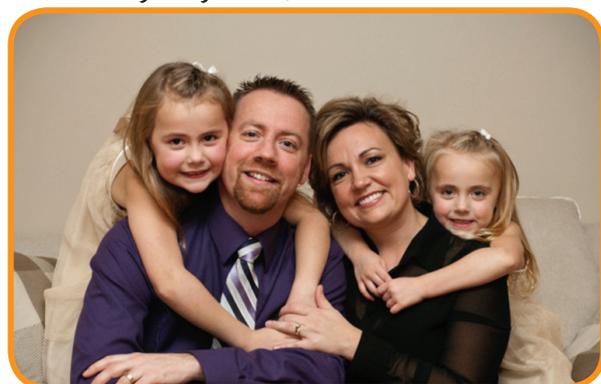
- Cigarette smoking remains legal in Canada. Sales of tobacco products remain widespread despite clear evidence of health risks including heart disease and lung diseases like emphysema, asthma and lung cancer.
- Smoking, while seen as a bad habit, is a powerful addiction.
- A person’s genetic makeup may predispose one person to lung cancer and prevent it in others, whether they smoke or not.
- Other environmental factors can also cause lung cancer, including second-hand smoke exposure, radon, asbestos or other workplace exposures.

Healthcare must not be judgmental. Healthier courses of action can, and should, be suggested to or even urged on patients. However, those who are sick for any reason do not deserve an added burden of guilt or stigma. People with heart disease aren't blamed for their smoking, nor asked how much unhealthy food they ate, or how little they exercised. People who are injured in risky sports or from bad driving aren't stigmatized in the emergency room. Similarly, those with lung cancer should not be judged.

Lung Cancer Canada believes that patients deserve the opportunities, care and public support afforded to other cancer patients. Reducing or even eliminating the stigma associated with lung cancer would be a major step forward in reducing the disparity.

"I still find that I have to justify my husband's disease to others. He was healthy, athletic and never smoked. He was still running regularly when he went to the doctor for a spot at the back of his eye. It turned out to be a secondary tumour from his lung cancer. That was three years ago. He was 40; our girls were 5 and 7."

- Natalie Deschamps, wife of someone living with lung cancer, Ottawa, Ontario



"The connection between lung cancer and smoking is very engrained in the public psyche. As a non-smoker with lung cancer, I run into a stigma about my illness from time to time. People just don't have broad exposure to people like me who end up with advanced lung cancer out of the blue."

- Mary Anne Phillipone, wife and mother who is herself living with lung cancer, Victoria British Columbia

DISPARITY #2:

TOLL – LUNG CANCER’S IMPACT ON CANADIANS

Whatever its cause in a given person, lung cancer takes a heavy toll that, very unfortunately, creates the most serious disparity between it and other cancers.³ Lung cancer is the..

#1 CAUSE OF CANCER-RELATED DEATH IN CANADA, IN BOTH MEN AND WOMEN

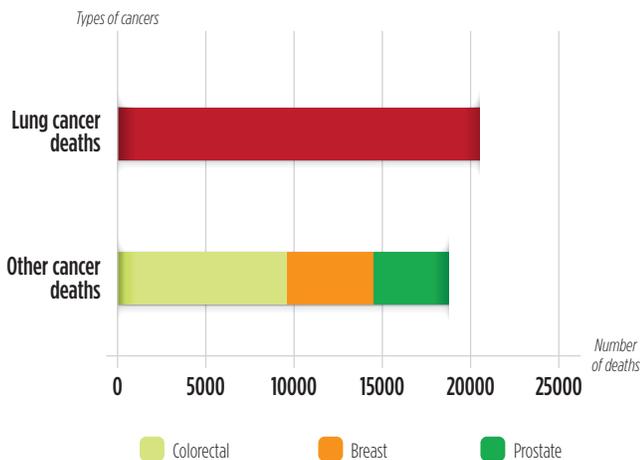
- MORE THAN **1** OUT OF EVERY **4** CANCER DEATHS IN CANADA (27%) IS **FROM LUNG CANCER**
- EVERY 27 MINUTES**, A CANADIAN DIES OF LUNG CANCER
- EVERY DAY** IT LEAVES HOLES IN 56 CANADIAN FAMILIES



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

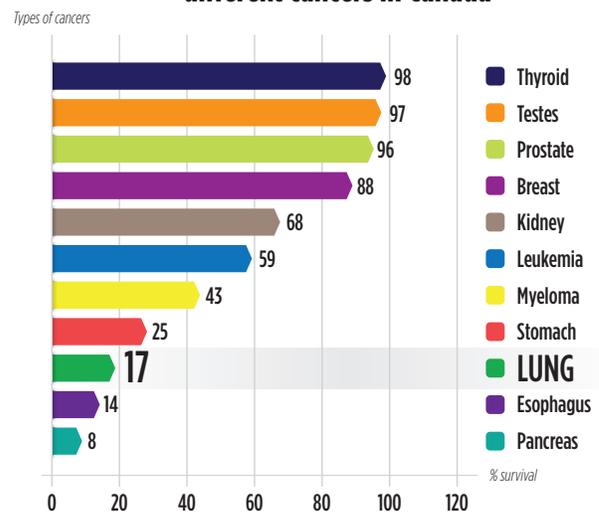
AT 17%, THE FIVE-YEAR SURVIVAL RATE FOR LUNG CANCER REMAINS THE LOWEST OF ALL THE MAJOR CANCERS.

Estimated cancer deaths in Canada, 2014



Source: Canadian Cancer Society, Canadian Cancer Statistics 2014, p. 45

Five-year relative survival rate for different cancers in Canada



Source: Canadian Cancer Society, Canadian Cancer Statistics 2014, p. 66

"When I was diagnosed with advanced lung cancer in December 2011, I was told I had six months to live. It was very difficult, but I was enrolled in a clinical trial and am still here in October 2014. After my diagnosis, I got all my affairs in order. That extra time has been very valuable. It has allowed me to wake up and dare to do things with my life I hadn't dared to do before."

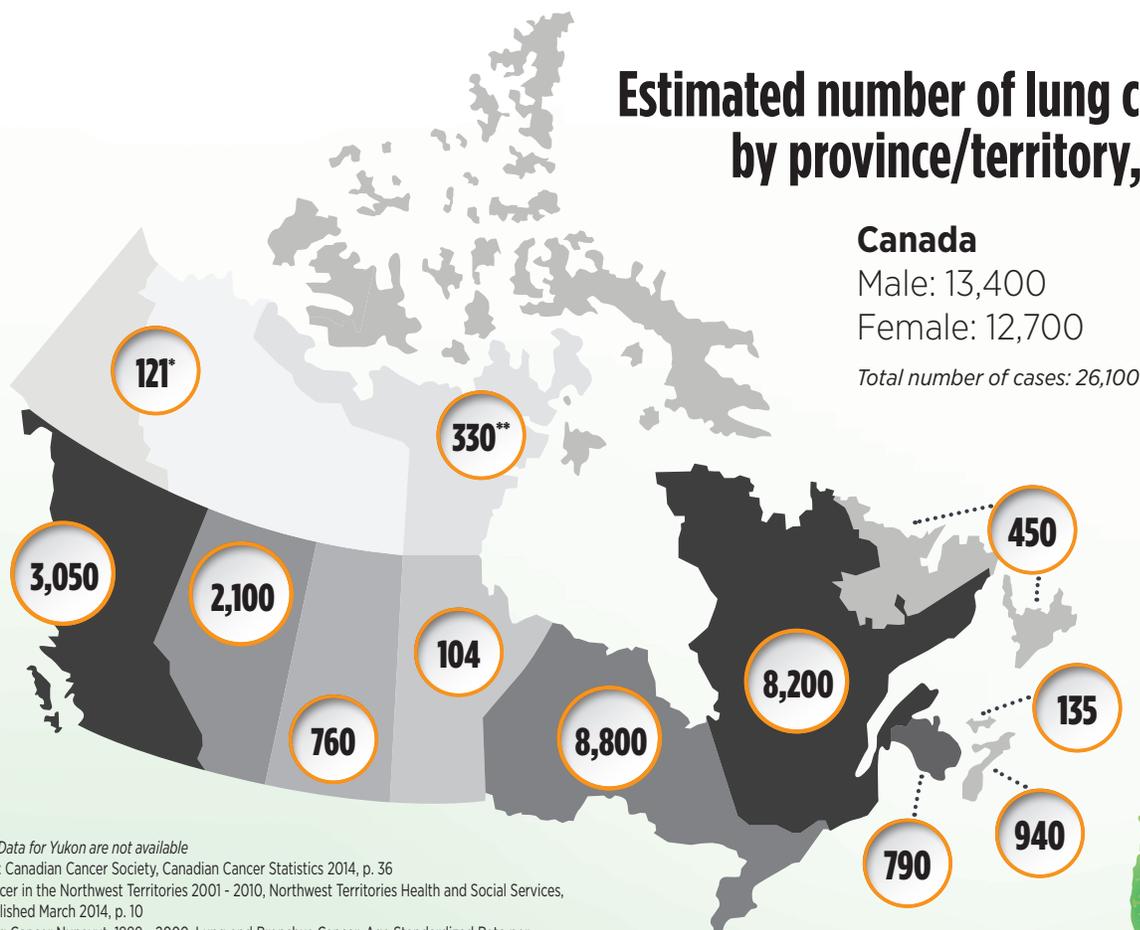
- Ruth Wasylenko, priest who is fighting lung cancer, Edmonton, Alberta



GENDER AND GEOGRAPHIC DISPARITIES ACROSS CANADA

There are important differences in lung cancer incidence and survival rates across Canada.

Estimated number of lung cancer cases by province/territory, 2014



NOTE: Data for Yukon are not available

Source: Canadian Cancer Society, Canadian Cancer Statistics 2014, p. 36

* Cancer in the Northwest Territories 2001 - 2010, Northwest Territories Health and Social Services, Published March 2014, p. 10

** Lung Cancer Nunavut, 1999 - 2000. Lung and Bronchus Cancer, Age Standardized Rate per 100,000 in 2010, published July 2013, p. 2. Accessed at: http://www.gov.nu.ca/sites/default/files/files/Lung_Bronchus_Final_16Jul2013%282%29.pdf

Estimated number of lung cancer cases per 100,000 population by gender and province, 2014

	BC	AB	SK	MB	ON	QC
Male	46 (1,500)	51 (1,050)	52 (360)	55 (430)	52 (4,500)	77 (4,300)
Female	41 (1,550)	44 (1,050)	51 (400)	49 (450)	42 (4,300)	60 (3,900)
	NB	NS	PE	NL	NT*	NU**
Male	75 (420)	68 (470)	72 (75)	70 (270)	(61)	(183)
Female	55 (370)	56 (470)	46 (60)	42 (180)	(60)	(147)

Numbers in brackets represent actual incidence numbers.

NOTE: Data for Yukon are not available

Source: Canadian Cancer Society, Canadian Cancer Statistics 2014, p. 36

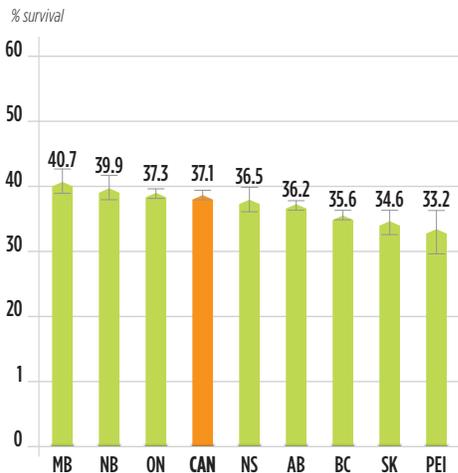
* Cancer in the Northwest Territories 2001 - 2010, Northwest Territories Health and Social Services, Published March 2014, p. 10

** Lung Cancer Nunavut, 1999 - 2000. Lung and Bronchus Cancer, Age Standardized Rate per 100,000 in 2010, published July 2013, p. 2. Accessed at: http://www.gov.nu.ca/sites/default/files/files/Lung_Bronchus_Final_16Jul2013%282%29.pdf.

WHERE YOU LIVE MATTERS

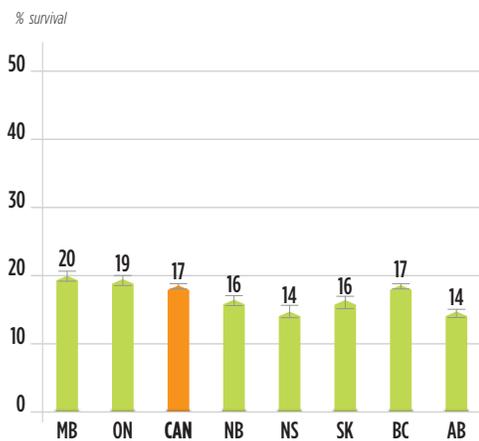
- British Columbia has the lowest incidence rates for both males and females.
- Quebec has the highest incidence rates for both males and females.
- One year relative survival rates from lung cancer range from 40.7% in Manitoba to 33.2% in Prince Edward Island.
- The Canadian Cancer Statistics do not include separate incidence rates for Yukon, Nunavut and the Northwest Territories. However, regional health authority reports indicate there are some large disparities in incidence and mortality between these areas and the rest of Canada. For example:
 - Lung cancer mortality in Yukon appears to be higher than the rest of Canada ⁴
 - Lung cancer mortality in NWT females is 1.5 times higher than the rest of Canada ⁵

One-year relative survival rates by province for cases diagnosed in 2001 to 2005



Data Sources: Canadian Partnership Against Lung Cancer, Lung Cancer in Canada: A Supplemental Systems Report, 2011; Statistics Canada, Canadian Cancer Registry

Five-year survival rates by province



Canadian Cancer Statistics, 2014¹

¹ Canadian Cancer Statistics excluded data from Quebec, in part, because the method for ascertaining the date of cancer diagnosis differs from the method used by other provinces and territories and because of issues in correctly ascertaining the vital status of cases. Canadian Cancer Statistics also excludes PEI as it was felt that the data are less precise than for other provinces because of the relatively small number of cancer cases in this province.

LUNG CANCER IS A WOMEN'S CANCER!

Lung cancer is by far the leading cause of cancer deaths for Canadian women, claiming 9,700 lives in 2014 – almost double the 5,000 women who will die of breast cancer and 20% more than the 8,050 who will die of all other women's cancers combined (breast, ovary, uterus and cervix).⁷

Canadian women die of lung cancer at a higher rate than countries such as the U.S., Australia, Germany and France. In fact, a 2013 report from the Canadian Institute for Health Information indicated that lung cancer death rates of Canadian women are almost twice as high as the 34-country average noted in the report.⁸

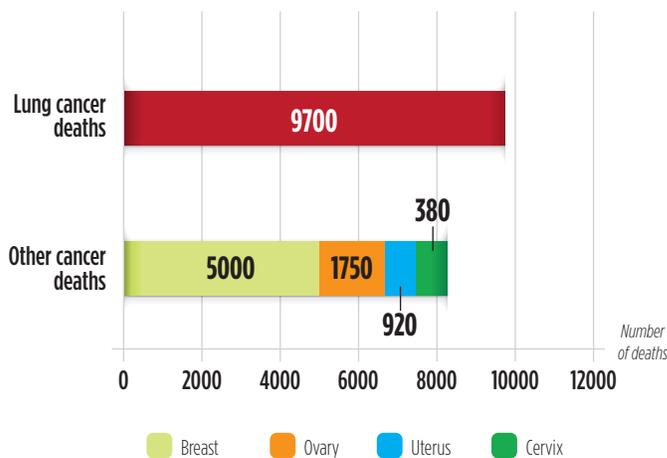
However, there is a huge disparity in women's awareness about the toll of lung cancer. In a recent national poll, only 11% of Canadian women identified lung cancer as the top cancer killer of women. Most (58%) named breast cancer and 13% said gynecological cancers.⁹

While lung cancer incidence and mortality rates have been declining for Canadian men for the past 30 years, they have steadily risen in Canadian women over this same time period.¹⁰

This change possibly reflects changes in smoking rates among men and women at different times in the past. BUT smoking cannot adequately explain the differences. Lung cancer develops differently in women than in men; research suggests that women tend to develop the disease at a younger age.¹¹

Rates of lung cancer are much higher among women who have never smoked than in men who have never smoked. This could be due to both genetic factors and increased exposure to second-hand smoke.¹² The profile of lung cancer as an important disease affecting Canadian women must be raised – it is a women's disease.

Estimated deaths of Canadian WOMEN from various cancers, 2014



Source: Canadian Cancer Society, Canadian Cancer Statistics 2014, p. 45

Lung Cancer Canada is striving to reduce incidence of disease and improve outcomes for lung cancer patients. Much more CAN and MUST be done for the over 25,000 Canadian families that will be affected by a lung cancer diagnosis this year.

DISPARITY #3: DIAGNOSIS – SCREENING AND TESTING

The disparity of lung cancer has two very different components related to diagnosis:

1. **Screening:** There is a lack of comprehensive screening programs for at-risk populations to detect lung cancer earlier and improve the chances of successful treatment.
2. **Molecular testing:** There is a growing need to understand the molecular profile of a patient's lung cancer in order to develop a treatment plan that is tailored to their personal cancer needs. This is now a reality in the treatment of cancers. Molecular testing is here to stay and needs to be readily available to all.



SCREENING

The earlier lung cancer is diagnosed, the better the opportunity for treatment as only cancers diagnosed at early stages remain potentially curable. Much of the great improvement that has been seen in survival in cancers such as breast, colorectal and cervical have been due to finding the cancers earlier through regular testing, even of those at just moderate risk, such as from age. However, almost half (48%) of lung cancer diagnoses are made only when the cancer is already at stage 4, the most advanced stage, meaning it has already spread outside the lung, and a further 27% of cases are diagnosed only at stage 3.¹³

Screening technologies that allow lung cancer to be detected at an earlier stage have advanced considerably. For many years, chest x-rays were the only method, but they were of limited value because they cannot reliably detect the smallest tumours, may give a false sense of security and have not shown benefit in clinical trials.

The newest screening method, low-dose computed tomography (LDCT) screening, offers much greater promise by yielding a more comprehensive view of the lung tissue while exposing patients to only 20% of the normal CT scan radiation. An expert panel convened by the Canadian Partnership Against Cancer in 2011 to review lung cancer screening reported that a comprehensive program of LDCT screening in Canadians at risk for lung cancer could be expected to save more than 1,200 lives per year, based on results of the National Lung Screening Trial in the U.S.¹⁴

In Canada, the Pan-Canadian Early Detection of Lung Cancer Study examined both how to incorporate lung cancer screening into our health care systems, and how much it would cost. This study found that **screening has the potential to save the health care system a significant amount of money**. In this study, the average cost to screen individuals at high risk for developing lung cancer using LDCT was \$453 for the initial 18 months of screening following a baseline scan. If a patient can be treated using curative surgery the average cost was \$33,344 over two years. This is significantly lower than the average per person cost of \$47,792 used in treating advanced-stage lung cancer with chemotherapy, radiotherapy, or supportive care alone.¹⁵

Lung Cancer Canada is committed to supporting and leading efforts to make lung cancer screening more accessible to Canadians at risk for lung cancer. We call on all provinces and territories to establish lung cancer screening pilot programs. Consideration for lung cancer screening should also be included in all provincial and territorial health care budgets.

MOLECULAR TESTING

Tremendous strides have been made in recent years that have identified several major genetic markers in lung cancer – mutations that differentiate forms of non-small cell lung cancer (NSCLC). From this, different new drugs have been developed to specifically target these mutations. These new targeted therapies are commonly oral therapies that can be taken at home. They are often more effective and have fewer side effects than traditional chemotherapy which is given through an intravenous infusion in hospital.

A sample of a patient's tumour is sent for molecular testing in order to learn if they may benefit from targeted therapy. Treatment is currently available for the following genetic markers:

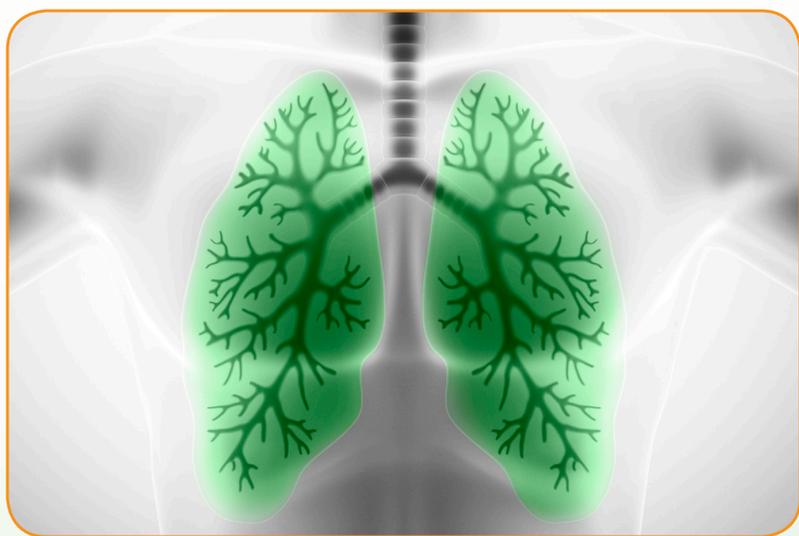
- **EGFR (epidermal growth factor receptor):** The gene that produces the EGFR protein is mutated in about 10-15% of NSCLC patients and in nearly half of lung cancers in those who have never smoked.¹⁶
- **ALK (anaplastic lymphoma kinase):** This test looks for the gene ALK fused abnormally with other genes, usually EML4. The EML4-ALK fusion is found in about 2% of NSCLC cases.¹⁷

As positive as all these developments are, they are only effective when patients have ready access to tests and timely results:



- Some centres get test results in three days. Others take six weeks. In the latter case, this may have significant consequences as some patients cannot wait for molecular analysis and have to start treatment with traditional chemotherapy, potentially missing their chance for targeted therapy.
- Successful molecular testing is contingent on having a sample of the patient's tumour available that is of sufficient size and quality. Not all biopsies result in sufficient tumour samples for the tests that could be done.
- Some centres test for EGFR and ALK at the same time; others do not, necessitating a time-consuming separate test if EGFR is negative and additional use of limited biopsy sample material.
- Many patients have to wait long periods for biopsy surgery and/or must travel to large centres to have it done – all while they are suffering the mental and physical effects of their disease.

The development of a pathology assessment pathway for lung cancer would provide clear guidance to institutions, professionals and patients of what could and should be expected, and in what time frames, to move patients quickly from diagnosis to a treatment plan customized to their particular form of the disease. This pathway is especially relevant as molecularly based treatments show much promise. Next generation EGFR and ALK treatments are in development and researchers are actively exploring treatments for other genetic markers in lung cancer. Advances are also being made to improve how molecular testing can be done. Next Generation Sequencing (NGS) is a new technology by which all relevant molecular questions can be answered in one test.



Lung Cancer Canada is committed to supporting and leading efforts to make molecular testing available as quickly as possible for all Canadians diagnosed with lung cancer to ensure they then receive the most appropriate treatment option.



"The 8 to 10 weeks it can take for us to evaluate and test lung cancer patients is an interminable amount of time for them, even though we are meeting our established time standards for each step of the process. So from the perspective of the system it looks like we are doing a good job. From the perspective of the patient, it is far too long."

- Dr Silvana Spadafora, Medical Oncologist, Sault Ste. Marie, Ontario

"Having sufficient and good samples of tissue to test can be a problem for us in our lab. We need to have at least 10 per cent tumour cells in a sample in order to conduct our tests and that isn't always possible."

- Dr Zhaolin Xu, Pulmonary Pathologist, Halifax, Nova Scotia

"Some centres send their EGFR and ALK tests to different facilities, which is both inefficient and requires more biopsy material. We're trying to implement platform testing to do all the tests at one time. We're using our hospital foundation funds to do it while we wait for Cancer Care Ontario."

- Dr Rosalyn Juergens, Medical Oncologist, Hamilton, Ontario

"I only found out about my lung cancer when I had my back pain checked and it was discovered to be caused by cancer metastases in my spine. My story supports early diagnosis and screening. With earlier diagnosis my lung cancer could perhaps have been detected earlier, instead of at stage 4."

- Col. Dr Jacques Ricard, recently diagnosed lung cancer patient, Ottawa, Ontario



DISPARITY #4: TREATMENT – ACCESS IS KEY

The ultimate goal for lung cancer treatment is: **“Getting the right treatment to the right person at the right time.”** In the case of lung cancer:

- For those diagnosed in early stage, this means timely access to a thoracic surgeon, and for later-stage patients this means access to a medical oncologist, radiation oncologists, palliative care services and best supportive care.
- New technologies such as molecularly targeted drugs and stereotactic ablative radiotherapy (SABR) mean that treatment and hospital processes must be continuously evaluated in order to ensure timely treatment.
- Canadians must have access to new and modern treatments. Patients who live in or close to major centres have access to world-class care. The geographic size of our country means that we need to ensure that those in smaller centres have the same access and opportunities to treatment as those in the larger centres.

“Some of my patients already travel a long distance to come to Sault Ste. Marie for treatment. Asking them to go to Toronto in order to access a special test or treatment, places an additional burden on them.”

– Dr Silvana Spadafora, Medical Oncologist, Sault Ste. Marie, Ontario

“We’re very lucky with the overall healthcare system that we have. The problem, however, is that not everyone has as prompt or complete access as they should to the services and treatments they need. I had to advocate strongly for myself to ensure I got what I needed. Not everyone is able to do that, so they miss out. That’s not fair.”

– Jessica Miller, 77-year-old lung cancer patient and advocate, Montreal, Quebec

ACCESS TO NEW TREATMENTS

A complex and time-consuming process is involved for cancer drugs to be evaluated for payment by each province after they are approved for sale in Canada by Health Canada. Individual provinces decide whether or not to pay for drugs.

The decision process can be long and time consuming and what results is a vast disparity in availability of treatments not just among different provinces, but even among individual hospitals in some provinces.

Lung Cancer Canada seeks speedier approval and payment for new lung cancer treatments for Canadians in as equitable a manner as possible for patients wherever they live across Canada.

"There's not too much we can't offer in terms of treatment, but maintenance therapies are difficult. The problem is that when the province approves a drug to be used, no money flows to hospitals to pay for it so each hospital has to decide on its own if it will make it available. It's very frustrating and complicated."

- Dr Jason Agulnik, Respirologist, Montreal, Quebec

"Oral cancer drugs to be taken outside the hospital are not able to be dispensed by our hospital pharmacies so patients have to be able to pay for them by themselves through private insurance or the provincial plan. However, about a quarter of patients have no plan whatsoever so we appeal to the drug companies to try to help them out. The patients are too busy dealing with their cancer - they're in no position to lobby or fight."

- Dr Tony Reiman, Medical Oncologist, Saint John, New Brunswick



DISPARITY #5: RESEARCH – CREATING HOPE FOR THE FUTURE

Many exciting and promising research and treatment developments are taking place in lung cancer. For example immunotherapies are showing much promise in treating lung and other cancers. They harness the power of the body's own immune system to fight the cancer cell. These drug therapies enhance the body's ability to recognize the cancer cells as "invaders" and kill them, as it does with viruses and other infections.

In 2014, lung cancer research has led us into the era of 'precision medicine'. Understanding the DNA fingerprint of the cancer allows researchers to develop new drugs that personalize therapies in many patients. New technologies, such as video-assisted 'keyhole' surgery, robotic surgery, and stereotactic body radiotherapy ('cyberknife'), allow precise and hi-tech therapies that minimize the risk of damaging normal tissues. Academic centres across Canada are researching and pioneering these methods in lung cancer.

All these developments mean that clinical trials can be an important avenue that provide patients with an opportunity to try innovative new treatments. However, access to trials can be difficult for some patients as they are usually only available in major centres.

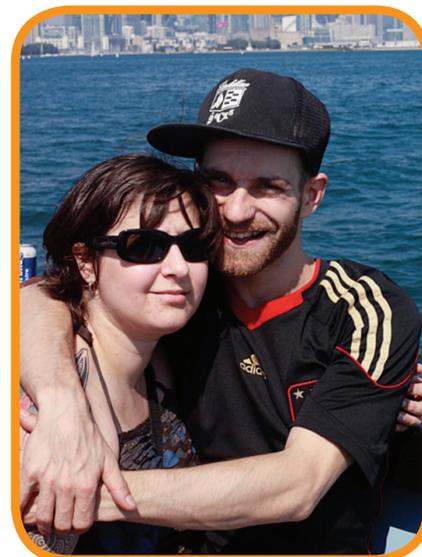
Yet despite the huge number of Canadians who lose their lives to lung cancer each year, and the exciting advances that are taking place, a huge disparity exists in the amount of research funding available to combat lung cancer.

While lung cancer accounts for more than a quarter of Canadian cancer deaths (27%), the disease receives only 7 per cent of cancer-specific government research funding and — even worse — less than one per cent of private cancer donations.¹⁸

Lung Cancer Canada is committed to working with governments and private donors to greatly increase the proportion of cancer research funds dedicated to lung cancer.

"I was told to wait to get treatment when I became symptomatic. I felt I was being put out to pasture at age 32. I read about a clinical trial for a new treatment and when I presented it to my medical team they were surprised. It bothered me that they didn't know about it. I got in the study and am now responding well to the targeted treatment. If it wasn't for a clinical trial and my advocacy for myself, I would be dead."

- Anne Marie Cerato, fiancée, daughter and sister who is fighting lung cancer (diagnosed at age 30), Toronto, Ontario



CONCLUSION

These are promising times for the fight against lung cancer. Exciting new progress is being made as our understanding of the disease increases greatly and new tests and treatments are developed.

However, there are still gaps in treatment and survival is low. We need to make sure research helps to bring about more choices for patients at all stages of diagnosis and treatment, and that those choices are readily available to all patients who could benefit from them.

We need to overcome the disparities present in the stigma, toll, diagnosis, treatment and research of lung cancer to ensure that in the fight against lung cancer in Canada we have all the important tools we need to have hope – and to win.

"Governments and our health systems need to realize that people get diagnosed with lung cancer and then actually LIVE with lung cancer. But we need testing, treatments and help to do that and our caregivers also need support to help us. We can't do it alone."

- Ruth Wasylenko, priest who is fighting lung cancer, Edmonton, Alberta

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