

2019 REPORT



LUNG
CANCER
CANADA



FACES OF LUNG CANCER

ACCESS, KEY TO #HOPEREALIZED

THE FACES OF LUNG CANCER REPORT

NOVEMBER 2019

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ACCESS IS CRUCIAL #HOPEREALIZED

2019 FACES OF LUNG CANCER FOREWORD



Anne Marie Cerato

A little more than a decade ago, I was a 30-year-old elementary school teacher in Toronto with a full and rewarding life. Sure, I felt more tired than usual, but I put that down to overwork. Then I noticed a small lump on my collarbone. Shortly after that, I saw my general practitioner, who ordered a chest X-ray after examining me. The X-ray revealed a shadow. Next, a CT scan called for a biopsy, which led to a devastating diagnosis: I had stage III adenocarcinoma lung cancer!

As anyone would be, I was stunned. Lung cancer? How was that possible? I had never smoked in my life, and like many people, I mistakenly thought that only smokers got lung cancer. Of course, I know better now. As I often say, “If you have lungs, you can get lung cancer.” In my case, the standard of care — radiation, chemotherapy, surgery — was prescribed. Two years later, my cancer progressed to stage IV non-small cell lung carcinoma with the mutated gene anaplastic lymphoma kinase (ALK). My situation had been dire before; now I was told I was terminal. However, I was able to qualify for a clinical trial of a treatment specifically targeted to ALK. I was in that trial for five years and then entered a second clinical trial for another targeted drug, which I am still in. During all this time, I have been able to live a pretty good life. I met a wonderful man and married him, and we even bought a house.

Living with lung cancer for 10 years is rare. I often call myself a unicorn. However, for there to be more unicorns like me, a

lot of things are critical: newer drugs; new ways to improve screening, diagnosis, and treatment; new strategies for delivery and funding of care. But along with all that, access is key. Chemotherapy, radiation, and surgery for lung cancer are fully funded in Canadian provinces, but for rarer mutations like mine, the cost of drugs can be prohibitive and may not be entirely covered by private or public insurance plans. Also, I live in Canada’s largest city. Many people across our nation, whatever kind of lung cancer they have, are in rural areas or much smaller places, and their access to screening, diagnosis, and care is far more difficult.

So what is my wish list for the access and treatment of lung cancer in the future? Better awareness of what can cause the disease. Earlier screening and diagnostics. Essential changes to how our health systems operate such as improving access to care closer to home, fully funded take-home drugs, eliminating the disparity between small and large centres for cancer treatment. Improved cooperation between governments and pharmaceutical companies to reduce the cost of new, innovative drugs.

The 2019 *Faces of Lung Cancer Report* that follows looks at many of these issues in detail to offer more examples of #HopeRealized and what we need to do to improve the different aspects of access to lung cancer care and treatment. Unicorns like me don’t need to be rare.

— Anne Marie Cerato

Anne Marie Cerato,
Dr Rosalyn Juergens and
Prof Raymond Laflamme

*Photo credit - Neal Burstyn
(NTB Creative)*



INTRODUCTION

PROGRESS BUT MUCH WORK REMAINS

#HOPEREALIZED

Lung cancer is the most commonly diagnosed cancer in Canada and is the leading cause of cancer death.

In the past years, progress in treatment has helped Anne Marie Cerato achieve her 10-year lung cancer “cancerversary,” while advances in screening have aided patients such as Debi Lascelle, who is featured later in this report and whose story was also told in the 2017 edition of the *Faces of Lung Cancer Report*.

Progress has helped the five-year survival rate for Canada’s deadliest cancer move from 17 percent to 19 percent, as reported in the Canadian Cancer Society’s Canadian Cancer Statistics 2019.¹ These are steps in the right direction, but much more work remains. Despite proven results like Debi’s and solid research evidence, screening is not universal across Canada.

Families, as seen later in this report in the story of Andrew McPhedran and his daughter, Rachel, are using GoFundMe to pay for cancer medications. Some provinces do not have access to diagnostic testing, treatment modalities, and even support programs.

Access is not universal and equal across Canada, but access to services and treatments are key components to fighting lung cancer in Canada and increasing survival rates, particularly since almost 50 percent of lung cancer is diagnosed at a late stage.²

Access is complicated by Canada’s vast geography and diverse cultures, as well as by how Canada’s healthcare system is set up. Healthcare is a partnership between federal and provincial governments. Health Canada, a federal body, approves drugs, but provinces oversee the listing and administration of healthcare.

The situation is complex, especially in this era of new surgical techniques and new treatments. Treatments have modernized, but it can be argued that our healthcare system has struggled to keep up.

Lung cancer patients are further disadvantaged compared to patients with other cancers, since currently lung cancer accounts for 26 percent of all cancer deaths and yet only receives less than 7 percent of the research funding.³

We must find solutions. Access is key to #HopeRealized. In the 2019 *Faces of Lung Cancer Report*, Lung Cancer Canada’s Medical Advisory Committee follows the patient journey and examines access, inequalities in access, barriers, and examples of best practices across the country. The committee examines factors affecting patient outcomes and provides suggestions to help improve access so that all Canadians living with lung cancer have an equal chance at #HopeRealized.

PROGRESS HAS HELPED THE FIVE-YEAR SURVIVAL RATE FOR CANADA’S DEADLIEST CANCER MOVE FROM 17 PERCENT TO 19 PERCENT.

MaryAnn Bradley



PART 1

THE CHANGING PARADIGM OF LUNG CANCER IN CANADA

HIGHLIGHTS OF 2019 LUNG CANCER STATISTICS

#19ISBETTERTHAN17

Every year the Canadian Cancer Society (CCS) produces a report that updates cancer statistics in Canada for incidence, mortality, and survivability. It also breaks down factors such as age, sex, and geographic location. In the 2019 CCS report, as in previous years, the leading cause of cancer death in Canada is still lung cancer.⁴

The statistics in Table 1 below show the picture of lung cancer in Canada in 2019. These statistics and the provincial differences (Table 2) are the starting point of our examination.

Other lung cancer highlights from the CCS 2019 report include:

- The estimated five-year survival rate for lung cancer in 2019 is 19 percent, an increase of 2 percent from previous statistics. The five-year lung cancer survival rate for females is 22 percent; for males 15 percent, while the ten-year 2019 lung cancer survival rate for females is 16 percent and for males, 11 percent.
- The highest incidence rates of lung cancer for both Canadian males and females are found in Nova Scotia, New Brunswick, and Prince Edward Island (see Table 2).
- For males, lung cancer mortality rates are highest in Quebec and the Atlantic Provinces, while for females the lowest is found in Ontario, with the highest in Quebec (see Table 2).

Table 1: 2019 Canadian Lung Cancer Statistics⁵

2019 Canadian Lung Cancer Statistics	
Number of cancer deaths due to lung cancer	1 in 4
Canadians who will be diagnosed with lung cancer in lifetime	1 in 15
Canadians who will die from lung cancer in lifetime	1 in 17
Most commonly diagnosed cancer for Canadian females	breast 25%, lung 14%
Mortality percentage of all cancers for Canadian females	lung 26%, breast 13%, colorectal 11%
Most commonly diagnosed cancer for Canadian males	prostate 20%, lung, 13%
Mortality percentage of all cancers for Canadian males	lung 25%, colorectal 12%, prostate 10%

Regional differences in incidence and mortality are able to help us identify areas of need. Overall lung cancer incidence and mortality rates are higher in Quebec and the Atlantic provinces than those in Ontario and British Columbia.

There are many reasons for differences in lung cancer rates among the provinces, some of which are due to differences in risk-factor rates. For example, Quebec has higher smoking rates, while many people in Atlantic Canada have poorer diets and lower incomes.⁶

Diagnostic practices and data collection methods may also differ between provinces. However, an important aspect is the availability and distance to healthcare services.

As we move forward in this report and examine the availability of health-care services, it is important to consider their impact on health outcomes. Lung cancer survival rates, as well as statistics for incidence and mortality, provide evaluation of the progress made in the treatment and control of this devastating disease. They also indicate where more still needs to be done.

Table 2: 2019 Lung Cancer Incidence and Mortality Rates by Gender and Canadian Province*⁷

PROVINCE	MEN		WOMEN	
	INCIDENCE	MORTALITY	INCIDENCE	MORTALITY
Alberta	60.1	45	58	41
British Columbia	54.4	42.9	53.4	39.1
Manitoba	70	49.9	63	46.3
New Brunswick	87.3	73.3	71.4	46.7
Newfoundland and Labrador	79.8	75.5	62.5	44.6
Nova Scotia	86.7	69.9	76	54.4
Ontario	67.5	47.9	59.6	36.3
Prince Edward Island	90.9	72.5	66	46.4
Quebec**		71.5		54.6
Saskatchewan	67.4	52.8	63.3	45.2

*Estimate rates are per 100,000 people. All estimates are from Canadian Cancer Statistics 2019, which is available at cancer.ca/statistics. Additional details on data sources and methods used to obtain these estimates are outlined in Appendix II of that publication. Cases are projected number of cancer diagnoses in 2019 based on data to 2015. Deaths are projected number of cancer deaths in 2019 based on data to 2015.

**Quebec estimates for incidence are not included because a different projection method was used for Quebec than the other provinces, meaning the estimates are not comparable.

Kim MacIntosh



PART 2

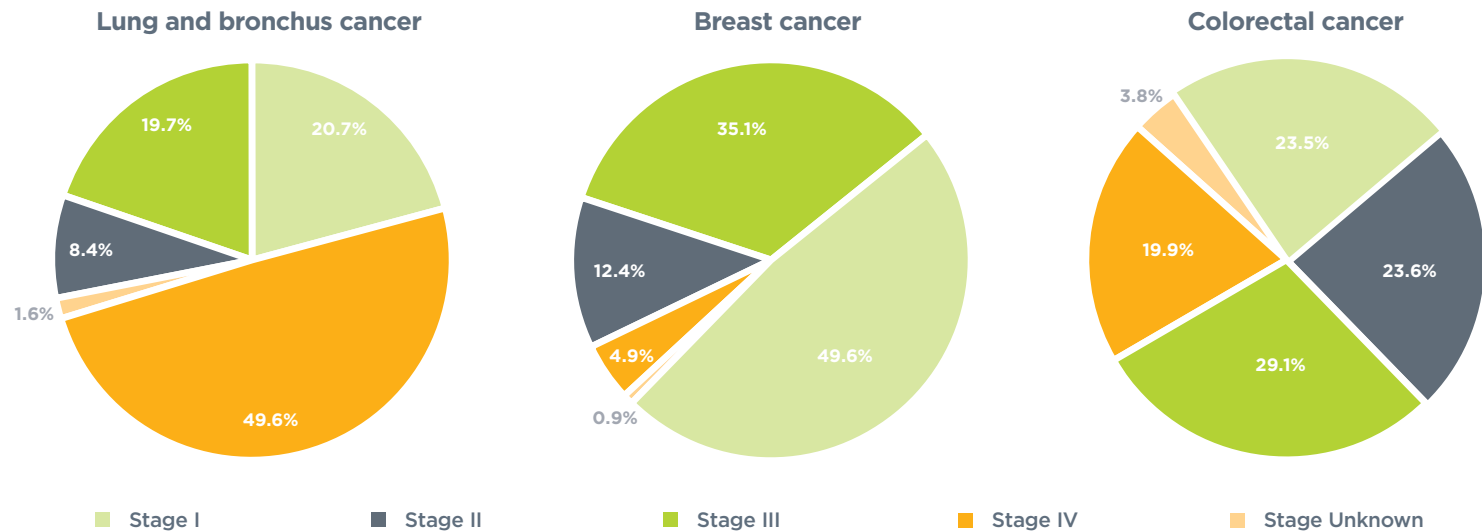
THE REALITY OF ACCESS IN CANADA

#ACCESSINCANADA

A diagnosis of lung cancer takes a patient and his or her family on a journey no one is ever able to prepare for. Inevitably, patients ask, “What are my chances?” or “Will I survive?”

Currently, for the majority of Canadians diagnosed with lung cancer, a positive answer to these questions is handicapped by a late diagnosis. Almost 50 percent of lung cancer is diagnosed at stage IV, an incurable stage. This compares to just under 5 percent of breast cancer and 20 percent of colorectal cancer diagnosed at stage IV (see Figure 1 below).

Figure 1 - Percentages of Stage Diagnosis for Lung and Bronchus, Breast, and Colorectal Cancers⁸



Analysis by: Health Statistics Division, Statistics Canada Data Source: Canadian Cancer Registry database at Statistics Canada

⁸Excludes Quebec ¹Includes cases diagnosed in people aged 18-79 years

LUNG CANCER SCREENING SAVES LIVES AND MONEY

#SCREENINGISCRITICAL

Early diagnosis is critical to improved survivorship and screening is key. Unlike other cancer-screening programs, current lung cancer screening guidelines only target those at highest risk. The Canadian Task Force for Preventative Health currently recommends lung cancer screening using low dose CT (LDCT) “for adults aged 55–74 years with at least a 30 pack-year smoking history who currently smoke or quit less than 15 years ago.”⁹ Annual screening up to three consecutive times is recommended. The evidence is strong. The Dutch-Belgium NELSON trial analysis of 10 years of follow-up showed a significant 25 percent reduction in lung cancer mortality in men and up to 61 percent reduction in mortality in women compared to those who were not screened.¹⁰ At this year’s World Conference on Lung Cancer, Canadian researcher Dr Stephan Lam presented data to show that the Canadian screening model detected more cancers than the screening model used in the United States.

Not only does lung cancer screening save lives, it also saves the system money. Canadian physician, Dr Sonya Cressman’s research indicates the mean per-person cost of treating lung cancer with curative surgery was \$33,344 over two years. This was significantly lower than the mean per-person cost of \$47,792 to treat advanced stage lung cancer with

chemotherapy, radiotherapy, or supportive care alone. The difference is even larger if targeted therapies or immunotherapies are employed.¹¹

Yet despite this evidence, as shown in Table 3 below, no province in Canada has adopted a publicly funded lung cancer screening program — in fact, many provinces do not even have pilot programs. The evidence is clear: lack of access to lung cancer screening programs will continue to act as a barrier to early diagnosis. As the cost of cancer treatments continues to rise, implementing lung cancer screening across the country would be both morally and fiscally responsible.¹²

Hand in hand with screening programs are smoking-cessation programs. Smoking-cessation support and clinics as well as nicotine-replacement programs are available but are limited in some Canadian provinces (see Table 3).

Smoking-cessation counselling and therapies can be efficiently incorporated into screening programs, and the infrastructure needs to become more prevalent in all provinces and territories, whether through municipal public health programs or provincial initiatives.

Presented at the World Lung Conference in Toronto this past fall, the Dutch-Belgium NELSON-trial, which is a population-based randomized control trial comparing CT screening with no screening in ever smokers between the age of 50 to 74 years who have smoked at least 15 cigarettes a day for 25 years or more or at least 10 cigarettes a day for 30 years or more and have smoked within 10 years. Between 2004 and 2006, the study enrolled 15,822 participants. The CT screening received a baseline CT and three additional screenings at intervals of 1, 2 and 2.5 years. Analysis at 10 years of follow-up showed a significant 26% reduction in lung cancer mortality in men and up to 61% reduction in mortality in women compared to the no screening group.

With two global, large randomized trials demonstrating significant mortality reduction, we now have clear evidence to support the implementation of lung cancer screening similar to breast and colorectal screening that save the lives of countless individuals.

New research projects are very important in the area of lung cancer. Despite being Canada's deadliest cancer killer, lung cancer receives some of the lowest funding for research compared to other cancers.

LUNG CANCER CANADA BELIEVES

All provinces and territories need to adopt consistent screening programs. Breast cancer and cervical cancer screening programs are widespread, but for lung cancer there is the need for comprehensive low-dose CT screening programs in selected populations, which should be linked with smoking-cessation services. Infrastructure needs to be put in place to provide patients with positive screening tests and appropriate diagnostic and follow-up services.

DEBI LASCELLE

Faces of Lung Cancer Patient Story

Debi was profiled in our 2017 *Faces of Lung Cancer Report*. Now 62 years old, Debi was first diagnosed with lung cancer nine years ago.

Back in 2010, she saw a newspaper advertisement for a study of people who were smokers or ex-smokers but held off applying, carrying the clipping around for a few months. When she did contact the Ottawa General Hospital, which was participating in the Pan-Canadian Early Lung Cancer Detection Study in eight cities across the country, she qualified and was able to take part in the study.

A CT scan revealed a lesion in her right lung, a biopsy was ordered, and the diagnosis came back that she had stage IA lung cancer. A PET scan and MRI determined that there was no other cancer in her body, and on Valentine's Day 2011, she underwent a lobectomy to remove a 13-millimetre adenocarcinoma from her right lung.

Debi's been cancer-free for eight years, takes no medications, and says she continues her yoga and works out as much, perhaps more, than she did before her diagnosis. "Of course," she quickly admits, "I won't be hiking up Mount Kilimanjaro." Still, she insists (and our medical advisory committee agree), without access to the early screening she had, she would likely not be here today. The study that Debi took part in, along with other screening studies, have shown that if lung cancer is discovered early enough, 70 percent of patients can be diagnosed at stage I or II.

When asked what she would like to see for the future of lung cancer treatment, she replies, "I hope that every Canadian province and territory adopts an organized, regular early screening program. We do it for breast, and colon cancer, so why not lung cancer? What's more, early screening, detection, and treatment of lung cancer saves money in the long run."

A former provincial court reporter, Debi is now retired and lives with her husband, John, who she's been married to for almost 30 years. After everything that she's been through, what does she have to say about her overall experience with the health system? She ponders that question for a moment, then affirms, "It's been very positive from the get-go. I have a lot of hope for the future and give a great deal of thanks for the dedication of all those who work so hard for lung cancer patients."



"I hope that every Canadian province and territory adopts an organized, regular early screening program. We do it for breast, and colon cancer, so why not lung cancer? What's more, early screening, detection, and treatment of lung cancer saves money in the long run"

-Debi Lascelle

GETTING TO A DIAGNOSIS

#ITMIGHTBECANCER

Debi Lascelle was diagnosed and treated as part of a study. However, as with all patients who are being investigated for lung cancer, there is considerable anxiety involved in “the wait,” “the wait” for further imaging, tests, and biopsies, and then “the wait” for the results. Anxiety levels correlate with “the wait” and increase as wait times escalate.

Rapid-diagnosis assessment programs (RDP) or diagnostic-assessment programs (DAP) can streamline the diagnostic process, help inform patients, and provide support. They help standardize how tests — for example, biopsies and diagnostic scans — are performed, leading to clearer and more comprehensive results. Importantly for patients, the RPD/DAP acts as a guide that helps them navigate the system and reduces “the wait.”

For instance, 59% of individuals suspected of having lung/thoracic cancer who were assessed through one of Ontario’s lung/thoracic RPD/DAPs were diagnosed within the 28-day target following a referral from their primary care providers or other healthcare professionals. This is moving closer to Cancer Care Ontario’s target of 65 percent.¹³ Yet despite proven effectiveness, RPD/DAPs are limited in some provinces such as British Columbia and Quebec.

LUNG CANCER CANADA BELIEVES

Rapid-diagnosis assessment programs (RDP) or diagnostic-assessment programs (DAP) are critical to efficiently assessing and diagnosing patients. They also provide psychosocial support to patients and help them navigate the healthcare system as they are being assessed. These represent best practices and should be supported across the provinces and territories.

In all cases, Lung Cancer Canada calls for better patient education and engagement through shared discussions and decision-making right from the diagnostic process, which would help foster better participation and improve navigation and patient satisfaction.

#MOLECULARTESTING

A positive diagnosis is just the start of the journey. Today, lung cancer treatment is very much driven by molecular pathologies: the presence or absence of molecular “signatures” in a patient’s lung cancer cells can determine oral targeted therapies versus intravenous treatments, chemotherapy versus immunotherapy, or even different combinations. The importance of molecular testing, which allows for a more personalized treatment, cannot be overemphasized. Standard practices in most provinces are individual sequential-tissue-based tests. However, this uses more tissue, which may limit the number of tests that can be run. There may also be a need for re-biopsy if there was not enough tissue in the original sample to run all the necessary tests. A more efficient methodology is to use a broader panel next-generation

sequencing (NGS) assay, which can evaluate all current and emerging biomarkers with a single test. Regardless of the testing methodology, wait times for test results need to be clearly communicated to patients in order to increase awareness and reduce anxiety.

Dr Xu comments, “this is complex science and we are navigating our way through, making note of the successes and failures to advance our understanding. The Canadian PD-L1 22C3 Quality Validation Project is currently taking place in more than a dozen sites across Canada, with the purpose of standardizing a non-kit based assay for PD-L1 expression. This kind of research can be a game-changer.”

Nivolumab and pembrolizumab are two anti-PD-1 antibodies that are approved after failure

of conventional chemotherapy for advanced NSLC in Canada. Nivolumab can be prescribed without biomarker testing for PD-L1 expression. Pembrolizumab is limited to patients with PD-L1-positive tumours. Pembrolizumab has also shown improved efficacy compared with platinum doublet in patients who are treatment-naïve with tumours expressing PD-L1 in 50% of tumour cells or more and is approved by Health Canada.⁴

The Expert Committee of thoracic oncology experts feels that PD-L1 testing should be readily available at the time of diagnosis of both non-squamous and squamous NSCLC to allow for rapid initiation of pembrolizumab to eligible patients.⁵ Health Canada approved pembrolizumab in the first-line setting in advanced NSCLC.

LUNG CANCER CANADA BELIEVES

Molecular testing is critical to matching patients to appropriate treatments, leading to improved patient outcomes. New technologies such as NGS should be continuously explored so they can become a cost-effective and efficient standard of care.

Regardless of the testing mechanism, Lung Cancer Canada believes that patients should be educated about the testing process, including the wait time for the results and the meaning of the outcomes in order to increase patients’ engagement and understanding of their cancers.

LAURA

Faces of Lung Cancer Caregiver Story

Navigating the healthcare system can be daunting for someone with lung cancer, or any disease for that matter, but it also poses challenges for a patient's caregiver. Laura knows that all too well now and during the past few years acting as an advocate for Michelle, her 65-year-old mother.

Late 2014 in Montreal, Michelle consulted her doctor about a persistent cold that wouldn't go away. The doctor felt Michelle, who was a smoker, had pneumonia, but also thought she might have a much bigger problem. X-rays and scans were called for, then a biopsy. Laura's mother had limited-stage small cell lung cancer (SCLC) affecting one lung and adjacent lymph nodes.

Laura says her experience felt like being in a nightmare and you can't wake up. While at the hospital in the spring of 2015 for their appointment to find out the diagnosis, they were handed Michelle's medical file. During the four hours they waited to see the doctor, they read the diagnosis for themselves. To find this out by reading her mother's medical file rather than hearing it from her doctor was particularly crushing. However, Michelle and Laura's voyage through the uncertain seas of lung cancer was only just beginning.

Language differences can play a role in complicating navigation. Laura speaks French, but her mother is more comfortable using English. Navigating the system when not in your first language proved too onerous, so they switched to an English-language hospital. However, the waiting list for scans there was too lengthy and eventually they transferred back to a French hospital, whose services were much faster.



Canada is now so multi-cultural that language barriers are common, and can cause stress and anxiety when trying to understand a new diagnosis and navigate through the system.

Michelle underwent standard treatment for SCLC in 2015. She stopped chemotherapy and radiation that year and had her last scan in the fall of 2016, which revealed that the cancer was gone.

In summing up her own experience as a caregiver and her mother's involvement with the health system, Laura says more emotional and mental support is needed for patients. When it comes to her mother, she says some of the issues that need to be addressed for all patients include language barriers, long wait times, inefficient scheduling, communication breakdowns, deficient integration of healthcare between the different medical specialties, and a lack of empathy. She also stresses the need for more training for health professionals so that patients will feel that the people and system are there to work for them.

Through all the process of her mother's care, Laura has often been emotionally drained and has felt that she was tilting in vain at windmills. However, she adds, "My mother lives with me now and is doing okay. Next year it'll be five years since her diagnosis."

Laura knows that's really something ... like winning a lottery.

#TAKINGCAREOFCANADA

Healthcare administration is a provincial responsibility. Each province has its own economy and outlook, which differ across the country.¹⁴ Geographical and population size differences also play a role, and the proportional access to specialist cancer centres also varies across provinces. Therefore, this means that cancer infrastructure and resources are not equal across Canada, which places further challenges not just on programs such as screening and rapid assessment, but also on the delivery of core services.

For example, PET scanners — a crucial test used in the initial diagnosis of lung cancer — are not available in Yukon, Prince Edward Island, and Newfoundland and Labrador. Sites for stereotactic body radiation therapy

(SBRT), cancer treatment that delivers extremely precise, very intense doses of radiation to cancer cells in a certain area while minimizing damage to healthy tissue, is not available in Newfoundland and Labrador or the territories. While surgical procedures, including thoracic surgery, video-assisted thoracic surgery, and endobronchial ultrasound (EBUS), are available in many Canadian provinces, there are gaps in terms of wait times and the need to travel for certain procedures.

Lung cancer patients living in Prince Edward Island and the territories routinely travel out of province, since none of the above-mentioned surgical procedures are available for them where they live.

LUNG CANCER ACCESS IN REMOTE PARTS OF CANADA

#TAKINGCAREOFREMOTECANADA

Differences between provinces are just one aspect of care. According to a 2014 Canadian Partnership Against Cancer report, Canadians in rural and remote areas have a higher incidence of lung cancer compared to those in urban areas. While reasons may be due in part to differences in smoking rates in less-urban communities, people in rural and remote areas may also have harder access to screening, diagnosis, and treatment services.

Many lung cancer management options available in big and medium-size cities in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, and Quebec are limited or not available in the remote northern areas of the same provinces or in Yukon, the Northwest Territories, and Nunavut.¹⁵

Dr Silvana Spadafora, a medical oncologist at the Sault Area Hospital in Sault Ste. Marie, Ontario, maintains that there is a need for access to

specialists, diagnostic techniques, and newer treatments in remote sites. Such access would substantially reduce travel to urban sites and lessen the burden on caregivers, since travel can take as long as six to 10 hours and much longer in the winter months. Furthermore, many Canadians in rural areas earn much less money than those in cities, which can also have a huge impact on patients and their caregivers. Travel and associated costs play a significant role in patients' acceptance or denial of treatment, increased stress, and financial burdens.

A healthcare partnership between the Northwest Territories and Alberta, as seen in the story of lung cancer survivor Alice Legat that follows, demonstrates what can be accomplished to improve the disparities between the North and South, remote and urban, when it comes to lung cancer.

LUNG CANCER CANADA BELIEVES

Patients need to be treated as close to home as possible while still maintaining excellence. The roles for community hospitals and regional centres of excellence in all provinces need to be better identified. Services such as additional chemotherapy infusion sites within smaller communities can help patients be treated closer to home and decrease wait times, as well as forge stronger linkages between community hospitals and regional centres and foster more intensive employment of electronic imaging and data exchange and consultation.

More intensive employment of electronic imaging, data exchange, and consultation through technologies should be encouraged. Services such as Telehealth should be universally adopted, since they can allow patients to interact remotely with health service providers, who will provide a variety of services that include diagnosis, treatment, education, monitoring, and support.

When travel is required, Lung Cancer Canada calls for better access to transportation travel grants in order to relieve financial and emotional stress.



Angus Pratt
photo credit Evan Pratt

ALLICE LEGAT

Faces of Lung Cancer Patient Story

For sparsely populated parts of Canada, access to specialized healthcare can be very difficult. With a population of just over 44,000 and 1.3 million square kilometres, the Northwest Territories (NWT) has had to develop innovative ways to serve the few people scattered over its vast geography. Allice, a practising anthropologist and writer, lives in Yellowknife, the territory's capital. Home to about 20,000 citizens, it's located 1,500 kilometres north of Edmonton, Alberta.

As early as 2013, she noticed she was feeling more tired than usual but put it down to age and asthma that become more aggravated by huge forest fires occurring in 2014. By late fall 2017, her tiredness had become overwhelming. Then, in January 2018, she developed a nasty case of pink eye and was told at the eye clinic to follow up with a doctor if it didn't clear up with the drops that were prescribed.

She did just that a month later, and the doctor detected a rattle in her lungs. Allice suggested it was asthma, while the doctor suspected pneumonia, but it was neither; she had a tumour. Allice was sent to Edmonton for an MRI and then a biopsy. By the spring of 2018, her diagnosis was confirmed as inoperable stage IV non-small cell adenocarcinoma with a tumour in the upper lobe of her right lung that had metastasized to right-sided pleura. Despite minimal smoking when she was young, there were no driver mutations identified in her tumour or in the blood, based on the Foundation One testing. Allice stresses that there are many factors that have been implicated in causing lung cancer in addition to smoking. These include radon gas, which is implicated in up to 15 percent of lung cancer deaths per year, and second-hand smoke. In May 2018, she was able to participate in a clinical trial of both chemotherapy and immunotherapy. Currently, Allice is in the maintenance stage and has an immunotherapy infusion every four weeks.



Allice Legat

photo credit Tessa MacIntosh

NWT patients with specialized needs such as Allice are cared for in Edmonton through agreements between the territory and Alberta. All NWT patients are eligible to travel to Edmonton for tests, treatment, and other medical help not available in the territory. The program picks up the cost of airfare as well as expenses for accommodation and food while in Alberta. Patients can choose to stay in the subsidized Larga House in Edmonton or in private accommodations with a limited allowance.

When asked about the travel program, Allice says, "Amazing. I think it's great We have access to good care even though we don't have specialists in the NWT. That doesn't mean there couldn't be improvements, though. It seems that people in the smaller communities have more difficulty working through the health system, as there seems to be inconsistencies concerning approval for patient escorts."

Asked how she feels now after a year and a half, Allice says her treatment shrank her tumour and it has been stable for several months. The oncologists hope that her stage IV lung cancer will become a chronic disease rather than a killer. "It really is a breakthrough that I can now walk up hills I couldn't walk up three years ago. And, more importantly, I stay up past 8:00 p.m. and at times even dance!"

"Moral support from the staff at Lung Cancer Canada, family, friends, and my oncological team," Allice insists, "have been extremely important to me for feeling positive. We have a women's group for cancer patients, my son and daughter-in-law are in Yellowknife, and I have friends who want to support my healing by escorting me to appointments in Edmonton and by sharing country food they harvest"

-Allice Legat

While this report has focused on interprovincial differences and geographic differences, it is important to also mention areas that Canada in general can improve on.

As an example, “pleural effusion” is a common complication of lung cancer in which liquid gathers outside the lung, squeezing it and leading to difficulty in breathing or shortness of breath that requires specialized care. Malignant effusion clinics, which help coordinate and provide such care including programs that drain the fluid in a patient’s own home, are limited across the country.

Additionally, psychosocial support and early access to palliative care are areas that all provinces in Canada can improve access to. There is solid evidence that earlier access results in better patient outcomes. When palliative care turns into end-of-life care, the wishes of patients, whether at home or in the hospital, should be provided through provincial support.

As our population ages, it is also important to understand the needs of Canada’s seniors, to recognize that the biggest risk factor for cancer is age, and to appreciate that Canadians are aging. According to Dr David Dawe, a medical oncologist at CancerCare Manitoba, there is a need for more comprehensive evaluations of seniors to better identify those who

are well enough to benefit from certain treatment modalities, those who currently may be undertreated or not treated at all, and also to identify the patients who are currently being offered aggressive treatments but may be too frail to handle the side effects.

An ideal model of care would be one where fit, older patients have equal opportunities to be considered for treatments as well as have better established mechanisms for determining those who are frail or vulnerable to frailty in order to tailor their treatments to their bodies’ capabilities. The number of seniors is expected to increase into the early 2030s, which means that a model of care that includes better consideration for this group of patients is crucial.

Canada is a big country, and we need to take care of our population. It is a social responsibility to ensure that no matter where you live, you have adequate access to needed healthcare services. Innovations, leadership, and collaboration among provinces are key to sharing resources to ensure timely and appropriate treatments. Patients such as Alice, Debi, and Michelle have had #HopeRealized. Improving on access to services will allow others to do the same.

Table 3 – Provincial Access to Lung Cancer Health in Canada

			AB	BC	MB	NB	NL	NS	ON*	PE	QC	SK	NT	NU	NT		
Screening			Widely available	Widely available	Not available	Not available	Not available	Widely available	Widely available	Not available	Not available	Not available	Not available	Not available	Not available	Widely available	
Diagnosis	RAPID-DIAGNOSIS ASSESSMENT PROGRAM		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Not available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	
	NEXT-GENERATION SEQUENCING PANEL		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Not available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
	INDIVIDUAL MOLECULAR TESTING	EGFR	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
		ROS1	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
		ALK	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
		BRAF	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
		PD-L1	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
PET SCANNERS		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	
Treatment	THORACIC SURGERY		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	
	VIDEO-ASSISTED THORASCOPY		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
	ENDOBONCHIAL ULTRASOUND		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
	RADIAL PROBE ENDOBONCHIAL ULTRASOUND		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
	MALIGNANT EFFUSION CLINIC		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
	STEREOTACTIC BODY RADIATION THERAPY	CHEST	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
		BRAIN	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
	RADIOFREQUENCY ABLATION		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
	ORAL TAKE-HOME CANCER MEDICATION		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
	PROVINCIAL REGIONAL CANCER CENTRES		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
	ADDITIONAL CHEMOTHERAPY INFUSION SITES		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available
Support programs	NICOTINE-REPLACEMENT PROGRAM		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	
	SMOKING-CESSATION SUPPORT/CLINICS		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	
	SPECIALIST PALLIATIVE CARE		Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	
	END-OF-LIFE CARE	HOME	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	
		IN-PATIENT	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	Widely available	

* In Northern Ontario, certain services are different from the rest of the province. For instance, screening, rapid-diagnosis assessment programs, and malignant effusion clinics are not available; limited diagnostic ability on-site for thoracic surgery (otherwise in Sudbury); next-generation sequencing panels only from the industry upon request; smoking-cessation support and clinics through public health; and nicotine-replacement programs publicly funded if there is no third-party payer.



Andrew McPhedran and family



PART 3

WHO PAYS FOR CANCER?

THE SHAPE OF DRUG FUNDING IN CANADA

#HOPEINFUNDING

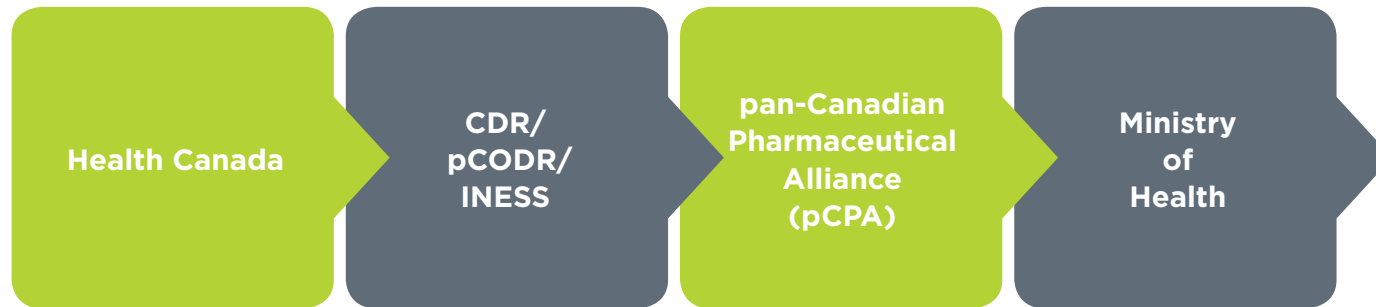
For Anne Marie Cerato, access to new treatments were key to being able to celebrate 10 years of living with lung cancer. The five-year survival rate for lung cancer in Canada, which remained fundamentally unchanged for years, rose to 19 percent in statistics reported in 2019.¹⁶ This has been in large part due to new treatments that have become available. Yet access to these treatments in Canada is still challenging.

As in previous years, Lung Cancer Canada provides tables detailing access to lung cancer drugs in our country, documenting the time from U.S. Federal Drug Administration (FDA) approval to Health Canada approval, the time it takes to receive positive funding recommendations from pCODR or INESSS (Quebec's Institut national d'excellence en santé et en services sociaux), and the time to provincial listing. The FDA was chosen as a baseline because it is often the first regulatory body to approve new treatments.

One part of these differences is due to when manufacturers choose to make an application for approval to Health Canada. However, it can be seen in Table 4 that in many cases the difference between FDA approval and Health Canada approval is relatively short. In one case, Health Canada's approval even came before FDA approval.

Most of the time noted in the tables that follow is due to our system and process. It is important to remember that Canada and the United States have fundamentally different healthcare systems. Whereas the U.S. system is primarily private-insurance-driven, Canada has a public healthcare system and thus has a system after Health Canada approval to ensure responsible use of public funds.

This Health Technology Assessment (HTA) process starts with pCODR or INESSS to assess the value of a drug: how well does it work compared to the standard treatment, does it meet patient values, what do clinicians feel about the new treatment. Following a positive pCODR or INESSS recommendation, confidential pricing negotiations begin and are conducted between the Pan-Canadian Pharmaceutical Alliance (PCPA) and manufacturers. Once a price has been agreed upon, the provinces then decide how and when to incorporate it into their provincial budgets.

Figure 2 — Drug Approval and Access Process in Canada

As lung cancer treatment has evolved, it is the HTA's more traditional definition of benefit and then value that is creating barriers to access. Lung cancer treatments are the leaders in targeted therapies, which has changed the paradigm of cancer treatment. Due to targeted therapies' ability to focus on specific molecular signatures in lung cancer cells, they have drastically increased response rates over traditional chemotherapy.

Many targeted therapies are approved by Health Canada with phase 2 data (these are usually smaller studies and not necessarily a direct comparison with the existing treatment). However, most targeted therapies submitted to pCODR using phase 2 data have received negative funding recommendations. All treatments that have been tested with phase 3 trials (larger, more expensive studies comparing the new drug with the existing treatment) have had to resubmit with phase 3 trial results rather than being able to use compelling phase 2 results.

Even more alarming, specific targeted therapies only serve very small subsets of lung cancer patients, so phase 3 trials are often not possible. This is the case with dabrafenib and trametinib, targeted therapies for

BRAF positive patients, who make up less than 1 percent of the lung cancer population. This has severely limited access for Canadian BRAF positive lung cancer patients.

On the other hand, part of the funding challenge is due to the cost of medications. According to the 2017 annual report of the Patented Medicines Pricing Review Board (PMPRB), from 2006 to 2017, the 28-day average treatment cost for oncology medicines increased by 82 percent, rising from \$3,867 to \$7,057.¹⁷ With more novel medications to come, these costs are projected to increase, which poses a significant challenge for a publicly funded system.

When medicines are not publicly covered and patients have no, or are denied, private insurance coverage, how can patients pay for the life-saving medicines they need?

For some people like Rachel McPhedran's father, Andrew, lung cancer has turned into GoFundMe disease.

ANDREW AND RACHEL MCPHEDRAN

Faces of Lung Cancer Patient and Caregiver Story

It started with a nagging backache. Andrew, who lives in Ottawa, was pretty active and used to back strains, so at first he dismissed the pain. But it got worse and worse. His doctor thought it might be an inguinal hernia, so he had an ultrasound. When the pain became so bad that he couldn't walk, a CT scan was ordered, followed by more tests. Then, in early December 2018, he was diagnosed with stage IV non-small cell lung cancer. As a lifelong non-smoker, 54-year-old Andrew was astonished.

Molecular testing in January 2019 determined that his cancer was positive for an epidermal growth factor receptor (EGFR) mutation. His doctors recommended osimertinib (Tagrisso®) as a first-line therapy because it is highly effective for EGFR+ tumours, has fewer side effects than older-generation EGFR inhibitors like afatinib, and leads to better life expectancy and quality of life for patients.

There was a catch, though. Although osimertinib has been approved by Health Canada and the pan-Canadian Oncology Drug Review, it isn't publicly funded by any province as a first-line treatment, though it is funded as a second-line drug in all provinces except Newfoundland and Labrador, Nova Scotia, and Prince Edward Island. So without access to a clinical study or private insurance coverage, osimertinib costs as much as \$9,000 per month. Andrew says that when he discovered that osimertinib would cost so much, he panicked.

Andrew McPhedran



But his daughter, Rachel, heard from a friend about GoFundMe campaigns that had raised funds for cancer drugs, so she thought they should try it. The family was very fortunate to have friends who were willing, generous, and able to donate, and things took off from there. The GoFundMe campaign has been very successful, and Andrew has been on osimertinib for the past nine months, the tumours are shrinking, and he is doing well on the treatment.

Patients and caregivers in Canada, including Rachel, are petitioning AstraZeneca, the manufacturer of osimertinib, and provincial governments to find ways to make the drug publicly funded so that other patients won't have to resort to crowdfunding campaigns to fund their treatments.

As for Andrew, who is 55 now, he says he hopes to see 56 “with a little bit of effort and a little bit of good luck and all those things that come into play”.

Lung cancer treatment should not be a GoFundMe campaign. Andrew was very fortunate that he was able to receive the treatment his physician felt fit best. But what happens if he is “really fortunate” and the drug works for so long that the GoFundMe dollars run out?

However, others, who are not able to find funding for treatments, are faced with difficult choices. What follows is Angus Pratt's story.

ANGUS PRATT

Faces of Lung Cancer Patient Story

Born in Scotland and raised in Saskatchewan, Angus is a 61-year-old freelance web developer and first-aid worker who now lives in Surrey, British Columbia. His mother died of breast cancer when he was in his late teens and his brother was diagnosed with the same disease 10 years ago. In early 2018, Angus says he knew he had something in his right breast but didn't do anything about it for a while. Then he finally went to see his doctor, who confirmed that he did have a lump in his right breast and one in the other breast, too.

An X-ray and ultrasound were scheduled, and the morning after, he was informed that a biopsy was necessary. Ten days later, he was told he had intraductal carcinoma of the breasts. As standard procedure, further CT and bone scans were done and a tumour was discovered in one lung, a shock to him since he had never smoked. This was followed with another biopsy, which determined that he had stage IIIC non-small cell adenocarcinoma. Subsequent molecular testing indicated that he had the epidermal growth factor receptor (EGFR) mutation.

The lung cancer was more urgent, so treatment for the breast cancer was put aside as he underwent six cycles of chemotherapy and 30 days of radiation. Six weeks after that, he had a bilateral mastectomy for his breast cancer. In September 2018, he was put on immunotherapy for the lung cancer. However, it didn't halt the growth of the tumour and his cancer progressed to stage IV by March 2019.

Angus's doctor recommended that he, like Andrew McPhedran, take the new drug, osimertinib (Tagrisso®).

But, as described in Andrew's story, the medication isn't publicly funded as a first-line treatment in any province in the country, despite being recommended by the pan-Canadian Oncology Drug Review. So, as a second option, Angus began taking afatinib (Geotrif®), which he's still on. Even though the afatinib has been effective so far, it has more side effects than osimertinib — weekly diarrhea, a nasty red eczema rash and pimples, slight cognitive lapses — and thus reduces his quality of life.

When asked about the lack of public funding for certain essential lung cancer drugs, Angus says, "Yeah, it's frustrating for me, and no doubt other patients. Governments and drug companies need to talk more to each other and work hard to resolve the pricing and funding issues. I know it's a numbers game, but people are suffering due to the intransigence of both parties."

A widower with three sons now after his wife, Yvette, passed away from pancreatic cancer in November 2018, Angus has endured a great deal since his original diagnosis more than a year ago. Nevertheless, he's recertifying as a first-aid attendant and enjoys triumphs when they occur. A case in point is when he got the all-clear on a recent brain scan as well as the news that nodules in his left lung had shrunk or even disappeared. "I hadn't realized how much everything had been weighing on me. I'm a Scotsman, pretty stoic, and don't let things get to me too much, but when I got the good news, there was a fist pump and I was a pretty happy boy. It was a moment when it was working. It was exciting."



Angus and Yvette Pratt
photo credit Delores Carter

Andrew and Angus both hoped to access a newer medication that, while having completed the HTA process, is still not funded by provinces. However, even in cases where the HTA process has been completed and provinces have listed the treatment, access can still be challenging.

Patients prescribed an oral take-home medication who live in Canada's western provinces are 100 percent covered by their provinces. Patients in Ontario and Atlantic Canada are not. For patients in these provinces, cancer treat-

ments administered in hospitals are fully covered and those taken at home are not. Applications to special programs for further coverage throw up administrative barriers and cause significant delays to access. Yet, according to Cancer-tainty, a coalition of Canadian patient groups, cancer health charities, and caregiver organizations working with oncologists and cancer-care professionals to improve the affordability and accessibility of cancer treatment, the additional cost to fully cover these treatments is small. For example, in Ontario it is estimated that an invest-

ment of \$28 to \$93 million, or roughly 1 percent of Ontario's total 2012 drug budget, will ensure all patients in Ontario have access to take-home cancer medications. The investment is also estimated to lead to at least a 17 percent reduction in overall chemotherapy unit costs. The same holds true, proportionally, for Newfoundland and Labrador, New Brunswick, and Prince Edward Island.¹⁸

How does the lung cancer community move forward and what happens from here?

LUNG CANCER CANADA BELIEVES

A dialogue and collaboration must occur between all stakeholders, including patients, clinicians, manufacturers, and HTA bodies, to discuss ways to modernize Canada's public system in order to improve access and affordability.

Personalized medicines are a key component to treating lung cancer, and as treatments include more targets, lung cancer patients will be subset into smaller and smaller populations.

Traditional phase 3 studies may mean patients have unnecessary wait times or may not even have access to the medicines they need. Explorations of new funding models, such as those where manufacturers risk-share with the funders,

are critical. Time-limited funding models and re-evaluation based on additional clinical or real-world evidence should also be explored. Oral medications need to be fully covered across the country.

Treatment of patients at home results in savings to the system. These savings, and those realized through new funding models, need to be reinvested back into the healthcare system so that access to cancer services and treatments throughout the cancer journey can be equal and timely through all regions and populations in Canada.

National pharmacare, with comprehensive, universal and equitable access to drugs across Canada, is called for by Lung Cancer Canada. For all lung cancer patients, access is key to #HopeRealized.

Table 4 – Date of FDA Approval to Health Canada Approval

DRUG Generic name brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	pCODR Status	Phase Data Used
afatinib (Giotrif®)	For the first-line treatment of epidermal growth factor receptor (EGFR) mutation positive, advanced non-small cell lung cancer (NSCLC) patients.	July 12, 2013	November 1, 2013	Final Recommendation May 2, 2014: Recommended pending cost-effectiveness	3
alectinib (Alecensaro®) 2nd line	As monotherapy for the treatment of patients with anaplastic lymphoma kinase (ALK) positive, locally advanced (not amenable to curative therapy) or metastatic NSCLC who have progressed on or are intolerant to crizotinib until loss of clinical benefit.	December 11, 2015	September 29, 2016	Final Recommendation March 29, 2018: Recommended pending cost- effectiveness	3
alectinib (Alecensaro®) 1st line	For the first-line treatment of patients with anaplastic lymphoma kinase (ALK) positive, locally advanced or metastatic NSCLC.	November 6, 2017	June 11, 2018	Final Recommendation July 25, 2018: Recommended pending cost- effectiveness	3
atezolizumab (Tecentriq®)	For the first-line treatment of patients with extensive stage small cell lung cancer (ES-SCLC) in combination with a platinum-based chemotherapy and etoposide.	March 18, 2019	August 8, 2019	Initial Recommendation October 3, 2019: Not recommended	3
atezolizumab (Tecentriq®)	For the treatment of patients with locally advanced or metastatic NSCLC who have progressed on or after systemic chemotherapy until loss of clinical benefit.	October 18, 2016	April 6, 2018	Final Recommendation June 20, 2018: Recommended pending cost- effectiveness	2 + 3
brigatinib (Alunbrig®)	For the treatment of adult patients with ALK positive metastatic NSCLC who have progressed on or who were intolerant to an ALK inhibitor (crizotinib).	April 28, 2017	July 26, 2018	Final Recommendation August 1, 2019: Not Recommended	2
ceritinib (Zykadia®) 2nd line	For treatment as monotherapy in patients with ALK positive locally advanced (not amenable to curative therapy) or metastatic NSCLC who have progressed on or who were intolerant to crizotinib.	April 29, 2014	March 27, 2015	Final Recommendation December 3, 2015: Not Recommended	2
ceritinib (Zykadia®) Resubmission 2nd line	For treatment as monotherapy in patients with ALK positive locally advanced (not amenable to curative therapy) or metastatic NSCLC who have progressed on or who were intolerant to crizotinib.	April 29, 2014	March 27, 2015	Final Recommendation March 21, 2017: Recommended pending cost- effectiveness	3
crizotinib (Xalkori®) Resubmission 2nd line	As monotherapy for use in patients with ALK positive advanced (not amenable to curative therapy) or metastatic NSCLC.	August 26, 2011	April 25, 2012	Final Recommendation May 2, 2013: Recommended pending cost-effectiveness"	3

Continued... Table 4 – Date of FDA Approval to Health Canada Approval

DRUG Generic name brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	pCODR Status	Phase Data Used
crizotinib (Xalkori®) Resubmission 1st line	Patients with ALK positive advanced NSCLC.	August 26, 2011	April 25, 2012	Final Recommendation July 21, 2015: Recommended pending cost- effectiveness	3
crizotinib (Xalkori®) ROS1	As a single agent as first-line treatment for patients with ROS1 positive advanced NSCLC.	March 11, 2016	August 28, 2017	Final Recommendation May 23, 2019: Recommended pending cost- effectiveness	1 + 2
dabrafenib (Tafinlar®) + trametinib (Mekinist®) 2nd line	In combination for the treatment of patients with metastatic NSCLC with a BRAF V600 mutation.	June 22, 2017	May 18, 2018 May 16, 2017 (previously treated with chemotherapy)	Final Recommendation November 2, 2017: Not Recommended (previously treated with chemotherapy)	2
dacomitinib (Vizimpro®)	For the first-line treatment of patients with locally advanced or metastatic NSCLC with EGFR activating mutations.	September 27, 2018	February 26, 2019	Final Recommendation May 31, 2019: Conditional Recommendation pending cost- effectiveness	3
durvalumab (IMFINZI®) Stage III unresectable NSCLC	For the treatment of patients with locally advanced, unresectable NSCLC whose disease has not progressed following platinum-based chemoradiation therapy (CRT), for follow-up to a maximum of 12 months.	February 16, 2018	May 4, 2018 NOC/c August 23, 2019 NOC	Final Recommendation May 3, 2019: Recommended pending cost- effectiveness	3
entrectinib (TBD)	For the treatment of neurotrophic tyrosine receptor kinase (NTRK) fusion positive, locally advanced or metastatic solid tumours in adult and pediatric patients.	August 15, 2019		Under Review	1 + 2
larotrectinib (Vitrakvi®)	For the treatment of adult and pediatric patients with locally advanced or metastatic solid tumours harbouring a Neurotrophic Tyrosine Receptor Kinase (NTRK) gene fusion.	November 26, 2018	July 10, 2018	Initial Recommendation August 29, 2019: Not Recommended for lung cancer	1 + 2
lorlatinib (Lorbrena®)	For the treatment of adult patients with ALK positive metastatic NSCLC who have progressed on crizotinib and at least one other ALK inhibitor, or patients who have progressed on ceritinib or alectinib.	November 2, 2018	February 22, 2018 NOC/c	Under Review	2
nivolumab (Opdivo®)	For the treatment of patients with metastatic NSCLC whose tumours express PD-L1 (as determined by a validated test) and who have disease progression on or after platinum-containing chemotherapy	March 4, 2015	February 26, 2016	Final Recommendation June 3, 2016	3

Continued... Table 4 — Date of FDA Approval to Health Canada Approval

DRUG Generic name brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	pCODR Status	Phase Data Used
osimertinib (Tagrisso®) 2nd line	For the treatment of patients with locally advanced or metastatic EGFR T790M mutation positive NSCLC who have progressed on or after EGFR tyrosine kinase inhibitor (TKI) therapy	November 13, 2015	July 5, 2016	Final Recommendation May 4, 2017: Recommended pending cost-effectiveness	2 (initial NOC/c based on phase 2 data) pCODR submission based on phase 3 data
osimertinib (Tagrisso®) 1st line	For the first-line treatment of patients with locally advanced or metastatic NSCLC whose tumours have EGFR mutations.	April 18, 2018	July 10, 2018	Final Recommendation January 4, 2019: Recommended pending cost-effectiveness	3
pembrolizumab (Keytruda®) 2nd line	For the treatment of patients with metastatic NSCLC whose tumours express programmed death-ligand 1 (PD-L1) (as determined by a validated test) and who have disease progression on or after platinum-containing chemotherapy.	September 4, 2014	April 15, 2016	Final Recommendation November 3, 2016: Conditional Recommendation based on cost-effectiveness	2/3
pembrolizumab (Keytruda®)	In combination with pemetrexed and platinum chemotherapy, for the treatment of metastatic non-squamous NSCLC, in adults with no EGFR or ALK genomic tumor aberrations, and no prior systemic chemotherapy treatment for metastatic NSCLC	May 12, 2017	March 13, 2019	Final Recommendation May 31, 2019: Recommended pending cost-effectiveness	2/3
pembrolizumab (Keytruda®)	For the treatment of patients with metastatic squamous NSCLC in combination with carboplatin and either paclitaxel or nab-paclitaxel, in adults with no prior systemic chemotherapy treatment for metastatic NSCLC	October 30, 2018	July 4, 2019	Under Review	2/3
pemetrexed (Alimta®) 2nd line	For maintenance following first-line pemetrexed and cisplatin for advanced or metastatic non-squamous NSCLC.	July 2, 2009	May 9, 2013	Final Recommendation November 19, 2013: Recommended pending cost-effectiveness	3
ramucirumab (Cyramza®) 2nd line	For the treatment of patients with advanced or metastatic NSCLC who progressed on or after platinum-based chemotherapy in combination with docetaxel.	April 21, 2014	July 16, 2015	Closed, not submitted	3

Table 5 — Date of Provincial Coverage

Drug Name	BC	AB	SK	MB	ON	QC	NS	NB	NL	PEI
afatinib	October 1, 2014	September 30, 2014	September 15, 2014	October 16, 2014	August 19, 2014	May 4, 2016	December 29, 2014	September 11, 2014	June 1, 2015	October 24, 2016
alectinib (1st and 2nd line)	May 1, 2019	Not Funded	February 11, 2019	May 31, 2019	Not Funded	February 1, 2019	Not Funded	May 16, 2019	Not Funded	Not Funded
atezolizumab	Not Funded	Not Funded	February 11, 2019	February 13, 2019	Not Funded	February 1, 2019	Not Funded	Not Funded	Not Funded	Not Funded
ceritinib	September 1, 2018	October 30, 2018	August 15, 2018	July 19, 2018	October 11, 2018	Not Funded	Not Funded	November 30, 2018	Not Funded	Not Funded
crizotinib (1st line)	December 1, 2015	December 18, 2015	December 28, 2015	January 18, 2016	December 4, 2015	February 8, 2016	May 2, 2016	April 12, 2016	February 1, 2016	August 1, 2018
crizotinib (2nd line)	March 1, 2014	October 31, 2013	October 3, 2013	October 17, 2013	October 1, 2013	February 3, 2014	December 1, 2013	November 8, 2013	April 1, 2014	April 8, 2014
crizotinib (ROS1)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
durvalumab	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	October 2, 2019	Not Funded	Not Funded	Not Funded	Not Funded
nivolumab	March 1, 2017	April 3, 2017	March 23, 2017	March 13, 2017	March 21, 2017	March 22, 2017	April 1, 2017	May 2, 2017	August 3, 2017	August 1, 2018
osimertinib (1st line)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
osimertinib (2nd line)	October 1, 2018	November 20, 2018	November 1, 2018	October 18, 2018	October 3, 2018	November 8, 2018	Not Funded	February 27, 2019	Not Funded	Not Funded
pembrolizumab (1st and 2nd line)	February 1, 2018	February 16, 2018	December 7, 2017	December 15, 2017	January 17, 2018	November 15, 2017	May 24, 2018	May 2, 2018	May 30, 2018	August 1, 2019
pembrolizumab (non-squamous NSCLC)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
pemetrexed	May 1, 2014	May 1, 2014	March 3, 2014	June 1, 2014	April 1, 2014	October 1, 2014	April 1, 2014	September 1, 2014	April 1, 2014	November 23, 2015

As of October 10, 2019

Table 6 — Number of Days from Date of FDA Approval to Date of Provincial Coverage

DRUG Generic name	FDA APPROVAL DATE	BC	AB	SK	MB	ON	QC	NS	NB	NL	PEI
afatinib	July 12, 2013	446	445	430	461	403	1027	535	426	689	1,200
alectinib (1st line)	November 6, 2017	541	Not Funded	462	571	Not Funded	452	Not Funded	556	Not Funded	Not Funded
alectinib (2nd line)	December 11, 2015	1,237	Not Funded	1,158	1,267	Not Funded	1148	Not Funded	1,252	Not Funded	Not Funded
atezolizumab	October 18, 2016	Not Funded	Not Funded	846	848	Not Funded	838	Not Funded	Not Funded	Not Funded	Not Funded
ceritinib	April 29, 2014	1,586	1,645	1,569	1,542	1,626	Not Funded	Not Funded	1,676	Not Funded	Not Funded
crizotinib (1st line)	August 26, 2011	1,558	1,575	1,585	1,606	1,561	1,627	1,711	1,691	1,620	2,532
crizotinib (2nd line)	August 26, 2011	918	797	769	784	768	893	828	805	949	956
crizotinib (ROS1)	March 11, 2016	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
durvalumab	February 16, 2018	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	593	Not Funded	Not Funded	Not Funded	Not Funded
nivolumab (2nd line)	March 4, 2015	728	761	750	740	748	749	759	790	883	1,246
osimertinib (1st line)	April 18, 2018	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
osimertinib (2nd line)	November 13, 2015	1,053	1,103	1,084	1,070	1,055	1,091	Not Funded	1,202	Not Funded	Not Funded
pembrolizumab (1st line)	October 24, 2016	465	480	409	417	450	387	577	555	583	646
pembrolizumab (2nd line)	September 4, 2014	1,246	1,261	1,190	1,198	1,231	1,168	1,358	1,336	1,364	1,792
pembrolizumab (non-squamous NSCLC)	May 12, 2017	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
pemetrexed (2nd line)	July 2, 2009	1,764	1,764	1,705	1,795	1,734	1,917	1,734	1,887	1,734	2,335

As of October 10, 2019

Dr Paul Wheatley-Price



PART 4

CONCLUSION

A MESSAGE FROM THE PRESIDENT

#HOPEFORTHEFUTURE

As we come to the end of another decade, it is a good time to review the progress that has been made in lung cancer treatment over the past 10 years while recognizing the challenges ahead at the dawn of a new decade.

Lung cancer remains the most common cancer in Canada. While in 2009 there were 23,400 cases, in 2019 more than 29,000 are anticipated, largely due to the growing and aging Canadian population. But sadly, lung cancer also claims more lives than any other cancer, with around 21,000 deaths projected in 2019. Actually, that isn't too different from the 20,500 deaths in 2009. While that is a depressing number there are clear signs of progress. The proportion of lung cancer patients surviving five years is actually increasing, from 15% in 2009 to an all-time high of 19 percent in 2019. Slow but real progress!

What must we do to improve on this, and what should our priorities be?

In September 2018, the lung cancer global community came to Toronto for the annual World Conference on Lung Cancer. We learned important information confirming the major role lung cancer screening can play in reducing lung cancer deaths through early detection. Today, half of lung cancer patients have stage IV

(incurable) disease when diagnosed, yet with CT scan screening there is the potential to diagnose hundreds and thousands more with earlier-stage disease with a realistic opportunity for cure. Disappointingly, lung cancer screening is not available for most of the Canadian population, while many of our peer nations are introducing programs. At time of writing, limited screening is available only in Alberta, British Columbia, Nova Scotia, Ontario, and Yukon; however, no programs are comprehensive and the future of each remains uncertain.

So with our first priority being access to new screening programs, our second priority is access to new treatments to improve and prolong the lives of lung cancer patients. There have been remarkable advances over the past decade such as the identification of molecular subtypes, and treatments targeting each of those subtypes with tablet medications. This has led to outstanding improvements in quality and quantity of life for those individuals. More recently, the emergence of immunotherapy, drugs that stimulate the body's own immune system to fight the cancer, has further dramatically altered treatment protocols and improved lives from coast to coast to coast. In my clinical practice, I daily see lives transformed for the better from these treatments.

Our challenge, though, is equitable access to these treatments across all provinces and territories. While we do well at ultimately approving most of these treatments, unfortunately we still see discrepancies in the time taken to approve new drugs in different jurisdictions, and grapple with some bizarre differences between jurisdictions that impact access based on age or the type of drug. Overall, it is still disappointing how long it takes for the regulatory process to be completed. Worryingly, we have also seen problems recently with access to commonly approved and well-established drugs due to manufacturing and distribution challenges. So in some situations we are having problems with our current treatments, let alone fighting for the newest ones.

The 2019 Faces of Lung Cancer Report highlights in more detail some of these challenges, while celebrating the successes we have seen. At Lung Cancer Canada, we are committed to raising awareness, advocating for lung cancer screening and access to treatments, and supporting the tens of thousands of patients and their loved ones facing lung cancer each year. Please join us in trying to turn lung cancer into a disease of the past.

— **Dr Paul Wheatley-Price, President of Lung Cancer Canada**

Ottawa Peer Group

Photo credit - Joelle Perrier



PART 5

WHO WE ARE

LUNG CANCER CANADA

#LCC

Lung Cancer Canada is a national charitable organization that serves as **Canada's leading resource for lung cancer education, patient support, research and advocacy**. Based in Toronto, Ontario, Lung Cancer Canada has a wide reach that includes both regional and pan-Canadian initiatives. Lung Cancer Canada is a member of the **Global Lung Cancer Coalition** and is the **only organization in Canada focused exclusively on lung cancer**.

Lung Cancer Canada's mission is three-fold: **1) to increase public awareness of lung cancer**, **2) to support and advocate** for lung cancer patients and their families, and **3) to provide educational resources** to patients, family members, healthcare professionals, and the general public.

Lung Cancer Canada also offers a **variety of resources** to educate and support patients and their families. These include: **1) our website**, which serves as a trustworthy and timely source of lung cancer information and news; **2) our newsletter**, Lung Cancer Connection, which explores topics of interest to the entire lung cancer community; **3) our Resource Library**, which allows patients and their families to access specialized information; and **4) our social media presence**, as well as the **discussion forums and patient stories** on our website, which offer lung cancer patients and families the opportunity to **connect and offer support to one another**.

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Lung Cancer Canada is a national charity and the only one dedicated solely to lung cancer. It relies on donations to offer programs and services, such as this booklet, to patients and their families.

Donations are greatly appreciated and a tax receipt is issued for a donation of \$20 or more. Donations can be made online at www.lungcancercanada.ca, or by calling the numbers above.

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