

2021 REPORT



LUNG
CANCER
CANADA



FACES OF LUNG CANCER

REFLECTIONS FROM COVID-19

THE FACES OF LUNG CANCER REPORT

NOVEMBER 2021

Lung Cancer Canada Volunteers -
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and Christina Amaral



WHO WE ARE

LUNG CANCER IN CANADA

Lung Cancer Canada is a national charitable organization that serves as a leading resource for lung cancer education, patient support, research and advocacy. We are a member of the Global Lung Cancer Coalition, and the only organization in Canada focused exclusively on lung cancer – a disease that continues to be the leading cause of death in this country.

Lung Cancer Canada's mission is three-fold:

1 Increase public awareness of lung cancer

2 Support and advocate for lung cancer patients and their families

3 Provide educational resources to patients, family members, health-care professionals, and the general public.

We also offer a variety of resources to educate and support patients and their families:



Our website,
www.lungcancercanada.ca
a trustworthy source of lung cancer information and news



Our newsletter *Lung Cancer Connection*, which explores topics of interest to the entire lung cancer community



Our resource library, which allows patients and their families to access specialized information



Our social media presence

-  @LungCan
-  @LungCancer_Can
-  @lungcancercanada



Discussion forums and patient stories on our website, which offer connection and support with others in the community

Each year, we publish the ***Faces of Lung Cancer Report*** – a report that gives a voice to the issues lung cancer patients and their families face today.

Thank you for taking the time to read, learn and advocate for those with this disease.

TABLE OF CONTENTS

INTRODUCTION

Current State of Lung Cancer in Canada

Page 1

Part 1

A PANDEMIC'S IMPACT ON PATIENTS

Snapshot

A Strain on Mental Health

Feelings of Isolation Mount

A Sense of Lost Time and Freedom

Access to COVID Vaccines

Page 6

Part 2

SPOTLIGHT: RISE OF VIRTUAL CARE

A Sudden Shift Brings New Opportunity

Beneficial When Used Appropriately

What Do Patients Say About Virtual Care?

A Changing Picture Province to Province

How Can We Strip Away Barriers to Improve Diagnostic Wait Times?

How Can We Improve the Patient Experience?

Page 17

Part 3

IMPACT ON PROVIDERS

Snapshot

Physician Burnout

Delays in the System

Greater Difficulty in Providing Nuanced, Specialized Care

Loss of Connection Among Care Teams

Delays in Medical Research Bear Consequences

Page 24

Part 4

ACCESS TO TREATMENT

Status of CADTH Drug Reimbursements

Date of Provincial Coverage

Number of Days from Date of FDA Approval to Date of Provincial Coverage

Page 34

CONCLUSION

Page 41

Dave Nitsche



INTRODUCTION

INTRODUCTION

As reported by the Canadian Institute for Health Information (CIHI), on January 25, 2020 came the first report of a Canadian with the COVID-19 virus. March brought federal recommendations on travel, self-isolation, work-at-home policies, and face mask use. It brought state of emergency warnings inside every province and the Assembly of First Nations.

Then, in the months that followed, we did our best to navigate our way through an ongoing pandemic. We made personal sacrifices, experienced difficult lessons – such as how quickly the virus can spread inside one facility – and experienced heartwarming moments when we could find them, such as the pots and pans porch banging and public appreciation for the ongoing efforts of front-line hospital staff.

By fall 2021, an estimated 50,000 Canadians were diagnosed with lung cancer during the pandemic. For the thousands more already living with lung cancer when COVID struck, their care changed dramatically, their access to treatments reduced, their support networks diminished, and their mental health declined.

The pandemic remains a novel health threat for which authorities and scientists and doctors alike have had to try to understand, forecast, and deal with on the fly. Its blanket effect on all communities has delivered newfound, challenging experiences for lung cancer patients, caregivers and healthcare providers.

Teams were forced to learn and adapt to maintain continuity of care as best as possible, and prioritize patient safety in ways unlike ever before. The hospitals many worked in experienced deep strain and high capacity as different waves and strains of COVID cycled throughout the country. When COVID cases were high in any particular region, local hospitals bore the brunt with patients spending long periods in ICUs.

Yet despite the gloomy conditions wrought by a pandemic, the past year was not without positive developments when it comes to lung cancer care and research. In times when negative news stories steal headlines and attention, it's important not to overlook important advances:

- **Many provinces now fully fund next-generation sequencing (NGS).**

This important step will allow more comprehensive testing for molecular subtypes of lung cancer, and ultimately access much broader range of treatments across Canada, accessible for lung cancer patients. Newly treatments include dabrafenib/trametinib for BRAF-positive non-small cell lung cancer, and larotrectinib for NTRK-positive non-small cell lung cancer. Over the next year, we anticipate applications and hopefully approvals for additional lung cancer subtypes such as MetEx14 mutation non-small cell lung cancer, RET fusion mutation non-small cell lung cancer, and KRAS G12C mutation non-small cell lung cancer. What all this means is that more and more lung cancer patients will have access to personalized targeted medications.

- **The early use of immunotherapy has such strong returns** that it has given rise to the hope that each person's outcomes for an operable cancer can be markedly improved. One important study, first reported in 2021, showed that the immunotherapy drug atezolizumab may significantly reduce

the risk of a recurrence after surgery. We await more promising data here and in other studies throughout 2022.

- **New lung cancer screening programs opened in Ontario** in addition to the announcement of a program in British Columbia in 2020. Quebec is now also opening a program, and we look for all provinces and territories to follow suit urgently. Lung cancer screening is vital to earlier diagnoses and to save lives.

- **We've watched the Health Technology Assessment (HTA) process in Canada turn far more progressive recently.** In rare subtypes of lung cancer, it is not possible to run large randomized trials because these diseases are so uncommon. But the HTA process is now accepting non-randomized research data when it comes to niche forms of lung cancer, such as BRAF mutations in non-small cell lung cancer and those who test positive for the rare ROS1-positive lung cancer. This enables access in Canada to targeted treatment for patients with these subtypes, which will direct far improved outcomes and a better quality of life.

These are important developments for which the community has advocated for some time, and we must recognize their potential for delivering beneficial impacts in years to come.

We also must celebrate the efforts of many lung cancer clinician-scientists who adjusted their work to take aim at COVID-19, playing valuable roles as respirology experts. For example, one team at Vancouver Coastal Health applied their research into new breath analysis techniques to diagnose lung cancer earlier in a bid to help fight the pandemic by developing a breath test that could identify volatile organic compounds that would indicate if someone was positive for the coronavirus.

Nonetheless, this document takes aim at the realities of living with, and treating lung cancer during a pandemic. It serves to capture the prevailing sentiments among the lung cancer community in Canada in hopes we can learn from the story and put the necessary supports in place for the future – pandemic or not.

Among those interviewed for this report, the single most impactful consequence of the pandemic for lung cancer patients was clear: fear and anxiety kept them away from hospitals, delaying diagnoses for critical months, disrupting treatment schedules, and exacerbating isolation. This is a story that can't be repeated.

While it will take another year or more to sort out how COVID has influenced trends and outcomes in lung cancer, one key lesson has emerged from oncologists across the country: the risk of catching COVID-19, or the next disruptive viral condition, is nowhere near the same level of having untreated lung cancer.

When a pandemic strikes, this community must double down and take greater pains to look after one another, and make the best possible decisions in the moment, as each choice carries long-lasting implications. Because when it comes to lung cancer, time is a luxury that cannot be wasted.

CURRENT STATE OF LUNG CANCER IN CANADA

Positive trends

While the most commonly diagnosed cancer in Canada continues to be lung cancer – nearly 30,000 new cases are estimated in 2021 – Canadian Cancer Society statistics contain some positive news when it comes to this difficult disease.

The survival rate at five years for people with lung cancer is now 22 per cent – up from 19 per cent reported in the Society's 2020 report, and 17 per cent in 2016. This is very significant, as 22 per cent is the highest rate ever recorded in Canada. While it remains well below the 64 per cent survival rate of all cancers combined, it is nonetheless a sign of hope and momentum.

The positive gains are in part due to a substantial drop in the lung cancer deaths among Canadian men in the past 35 years, as well as a similar but more recent drop among women. Overall across the country, cancer death rates have decreased in this country by 37 per cent in males and 22 per cent in females since ever their peak back in 1988.

What's more is that an adult's lifetime risk of being diagnosed with lung cancer is now one in 15 – up from one in 12 in 2016. And the lifetime risk of death by lung cancer is one in 19 – up from one in 15 in 2016.

We must continue the fight...

While positive trends are very welcome, and reflect the progress made in screening and treatments, this is no time to retreat into complacency when it comes to managing this devastating disease.

Lung cancer is not only the most common cancer in Canada but also the leading cause of cancer-related death. It is responsible for more deaths among Canadians than the other three major cancer types combined (colorectal, breast and prostate). This year alone, 21,000 patients are expected to pass away from this disease.

Indeed, lung cancer remains one of the most difficult diagnoses a patient and their families can receive – and, on average, 81 Canadians will receive that life-changing news each day.

NEW PROJECTIONS ON LUNG CANCER FOR 2021

NO. 1

**MOST COMMONLY
DIAGNOSED
CANCER IN CANADA**

21,000

**PATIENTS
WILL PASS AWAY
OF LUNG CANCER**

29,600

**CANADIANS
WILL BE DIAGNOSED
IN 2021**

**LUNG CANCER IS
THE CAUSE OF**



**OF ALL
CANCER DEATHS**

**LUNG CANCER'S
SURVIVAL RATE IS**



**COMPARED TO 64% FOR
ALL CANCERS COMBINED**

**LUNG CANCER AS
A PERCENTAGE**



**OF ALL NEW
CASES OF CANCER.**

**DAILY
RATE**



**NEW LUNG CANCER
DIAGNOSES ACROSS CANADA**

1 IN 15

**CANADIANS
WILL DEVELOP
LUNG CANCER IN
THEIR LIFETIMES**

The impact of COVID-19 remains unknown

There is so much we do not know about the state of lung cancer in Canada in 2021. Due to the nature of data reporting, cancer incidence data drawn to 2017 and cancer mortality data to 2019 were used to estimate the situation in 2021.

As a result, they almost certainly do not reflect changes in diagnosis and outcomes impacted by the main focus of this report: COVID-19. It will indeed take some time before a true understanding of the pandemic’s impact on screening, treatments, research and patient journeys comes into focus.

As the Canadian Cancer Society notes in its latest report, it will be vital to explore the influence of COVID-19 on lung cancer statistics when data

become available. In the meantime, this report offers a qualitative look at the situation on the ground in real-time across Canada, told through the lens of both provider and patient.

It’s a story that must be told today. Because despite some encouraging trends, we cannot be complacent in efforts to drive and fund important research projects, to implement greater screening programs coast-to-coast, to address systemic gaps around access to care, to better support the mental health needs of patients, families and clinicians, to prepare for any emerging dilemmas left in the pandemic’s wake.

To healthcare practitioners, researchers and patient advocates: let’s continue the hard work needed to further reduce the impact of this disease on Canadian families.

Across Canada, age-standardized incidence and mortality rates for lung and bronchus cancers in 2020 show*:

2021 Lung Cancer Incidence and Mortality Rates by Gender and Canadian Province

PROVINCE	MEN		WOMEN	
	INCIDENCE	MORTALITY	INCIDENCE	MORTALITY
British Columbia	55.2	42.0	54.3	39.8
Alberta	62.9	44.1	58.1	38.5
Saskatchewan	63.6	49.2	66.6	43.9
Manitoba	61.2	48.3	56.3	43.1
Ontario	59.9	45.0	56.2	35.4
Quebec		64.7		50.7
New Brunswick	90.6	65.2	68.0	44.6
Nova Scotia	84.0	60.4	74.9	51.3
P.E.I.	68.4	58.0	69.8	48.3
Newfoundland	77.9	65.7	68.3	44.4

*Estimate rates are per 100,000 people. All estimates are from Canadian Cancer Statistics 2021. 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.

James Tilley (left)
and Stephen Sallows (right)



PART 1

A PANDEMIC'S IMPACT ON PATIENTS

SNAPSHOT

The COVID-19 pandemic is of great significance to Canadians with lung cancer, as well as those yet to be diagnosed. As the months went on – and continue to, today, as of this report’s development in fall 2021 – these patients experienced a wide variety of life adjustments, all of which influenced their care, their mental health, their outcomes, families, and their lives overall.

Our medical community unquestionably performed at a high level to maintain continuity of care for lung cancer patients, within new and difficult circumstances. Nonetheless, the pandemic forced many changes. At the start, many medical appointments were rescheduled, deferred or adjusted.

In some centres, surgeries were delayed, access to treatments was often impacted, and clinical trials ground to a halt. Diagnoses were critically delayed due to patients staying home, and in reduced access to testing.

Then came the arrival of virtual care, an emergence that is a story unto itself (this report contains a section devoted to the subject), offering greater accessibility to health-care teams for patients, albeit in an unideal fashion.

For Canadians who didn’t yet know they had lung cancer, the pandemic was especially dangerous. As detailed in this report, people were reluctant to visit hospitals for fear of COVID, which has led to more patients being diagnosed with later-stage cancer. That has been combined with a scattered approach to lung cancer diagnosis from province to

province, with different screening programs impacted by COVID in different ways across the country.

We won’t have accurate data until late 2022 at the earliest about this “stage migration” but oncologists agree they are seeing a sharp uptick in cases of advanced lung cancers – a detrimental trend for Canadians living with this disease.

It will likewise be some time before we understand how COVID impacted lung cancer patients from an overall health perspective. According to a [review](#) in *British Medical Journal* in March 2021, we do know from registry data in many countries that these patients are extremely vulnerable to infections and poor outcomes – including having a higher risk of death from COVID than patients with any other cancer.

That vulnerability, confusion around accessing care, and the broad uncertainty around the pandemic, led to far greater anxiety and isolation among these patients already living with a difficult disease. (These two significant effects of COVID are explored in this section.) An uneven vaccine rollout, particularly on second doses, further blurred the picture for lung cancer patients.

This chapter details the personal and broad ways that Canadians with lung cancer were impacted by arrival of COVID. It is intended to bring these stories into the light, so that we can understand and apply learnings to the future.



Terry & Joyce Morey

A STRAIN ON MENTAL HEALTH

Across Canada, patients with lung cancer faced heightened anxiety, fear and stress about the threat of COVID-19 on their compromised health.

Our 2021 patient survey found that 44 per cent of respondents were hesitant to visit the hospital or their doctor's clinic during the pandemic. Meanwhile, nearly 90 per cent of respondents said that systemic delays and slow bookings caused by COVID restrictions caused them increased anxiety.

“A diagnosis of lung cancer is already a highly stressful time, with anxiety about what the future may bring, treatments, side effects and impacts on independence and on loved ones,” says Dr. Paul Wheatley-Price, a medical oncologist in Ottawa. “To be doing this in a pandemic, with all the associated restrictions, raises these stresses to new levels.”

In Edmonton, Dr. Quincy Chu says that anxious patients have frequently refused to go to emergency when they aren't well. “They may call our clinic later that day, and we can't do anything but advise them to go to the ER right away. It turns out that some have a pulmonary embolism in their lung, and even then they refuse to stay at the hospital for fear of COVID. That anxiety has a real impact in causing negative outcomes.”

One survey respondent highlights this fear: “I had an appointment with my oncologist, however I was very stressed to go to the hospital for my CT scan since it was the prime COVID hospital.”

Other respondents remarked that their anxiety and depression in turn negatively impacted their family.

“I HAD AN APPOINTMENT WITH MY ONCOLOGIST, HOWEVER I WAS VERY STRESSED TO GO TO THE HOSPITAL FOR MY CT SCAN SINCE IT WAS THE PRIME COVID HOSPITAL”

SURVEY RESPONDER

Anxiety impacting outcomes

These widespread feelings would seem to be directly influencing lung care outcomes. People who are diagnosed with lung cancer already face worry and anxiety, and it can cause them to miss or delay treatments. COVID has clearly made this considerably worse.

Dr. Stephanie Snow, medical oncologist in Halifax and president of Lung Cancer Canada, says they are seeing patients presenting far more frequently at later stages of lung cancer – and sicker. While it will take years to pinpoint this issue by studying epidemiologic data, Dr. Snow says that we have taken a step backward in terms of lung cancer outcomes.

“There may be a migration to more patients being stage three or four because they didn't visit emergency,” she says. “We are already seeing more people who are in untreatable stage fours – and more stage threes whose cancer has spread regionally, who would have been surgical candidates if stage one or two.”

Canadian Institute for Health Information [data](#) shows that from March to June 2020, cancer surgeries dropped by 20 per cent. Facts like these, coupled with first-hand experience at centres, has raised the spectre of a [flood of new cancer diagnoses](#), presenting at later stages, coming post-pandemic.

“Patient volume might be lower, but lung cancer didn't go away. This isn't about fewer cancers but that patients aren't being seen,” says Dr. Snow. “Meanwhile, we see an increase in those who come in so sick that they need to go straight to palliative care.”

This is a dangerous plot point in the story of COVID-19 and lung cancer in Canada. Out of worry during such uncertain times, people aren't getting the timely, necessary care they need, because they want to stay safe in their perceived bubble instead of heading to the hospital.

Trends to learn from

Bonnie Leung, a Vancouver nurse practitioner at BC Cancer Agency, describes one story that demonstrated this trend early in the pandemic. One patient with end-stage lung cancer was very symptomatic but refused to come to the hospital due to the threat of COVID. That fear also led her to refuse in-home nursing support as well, and her husband became an overwhelmed primary caregiver.

“She collapsed at home, was then transferred to hospital where she had to stay by herself, and in the end she died alone,” Bonnie says. “No one deserves to die like that.”

As an extension of this, doctors also report more patients who are electing to decline treatments for their lung cancer. Dr. Snow says she is seeing people settle for less effective treatments because it is more convenient and less involved logistically so they can stay at home.

“We have clear evidence for adjuvant chemotherapy for patients with resected lung cancer, which improves survival rates at five years,” Dr. Snow says. “But it’s a conversation with each person, because the therapy can have significant adverse effects. COVID served as another factor to sway their decision, because they don’t want to visit the hospital. Outside of COVID, they would be more likely to accept that chemotherapy. I expect this may lead to higher rates of recurrence in the future because fewer people chose to take the path to curative treatment.”

Dr. Normand Blais, a medical oncologist in Montreal, says a study will be necessary to spot trends in people delaying or simply not getting treatment caused by COVID alarm. “During the pandemic many of my patients were at an operable stage on their first scan, but by the time they got to surgery, they were inoperable,” he says. “This is becoming worse, as we now see this scenario on a weekly basis.”

“DURING THE PANDEMIC MANY OF MY PATIENTS WERE AT AN OPERABLE STAGE ON THEIR FIRST SCAN, BUT BY THE TIME THEY GOT TO SURGERY, THEY WERE INOPERABLE...THIS IS BECOMING WORSE, AS WE NOW SEE THIS SCENARIO ON A WEEKLY BASIS.”

DR. NORMAND BLAIS, MEDICAL ONCOLOGIST, MONTREAL

FEELINGS OF ISOLATION MOUNT

For lung cancer patients in any community, despite the available means to connect virtually with others, COVID brought a new kind of isolation that can develop when living with chronic disease.

Dr. Normand Blais found himself urging his patients to break free of isolation, to be social and be outside in a safe manner, because he knows that social isolation is proven to worsen cancer outcomes. For instance, a [2018 study](#) out of BC Cancer published in the *Journal of Clinical Oncology* found that socially isolated patients with metastatic cancer have inferior survival rates.

“Some of my patients isolate themselves to the point that they are scared to step foot in the grocery store,” Dr. Blais says. “As if there wasn’t enough to deal with having lung cancer, undergoing chemotherapy, now there is this other threat looming that seems so dangerous. I saw patients deciding how they want to spend what may be the last year of their life, deciding if they should shelter from COVID or see loved ones.”

In some cases, the pandemic hurt those family ties. Says one survey respondent: “Some family members aren’t vaccinated and don’t understand how as a lung cancer patient with only one lung, I cannot visit them.”

“SOME OF MY PATIENTS ISOLATE THEMSELVES TO THE POINT THAT THEY ARE SCARED TO STEP FOOT IN THE GROCERY STORE...AS IF THERE WASN’T ENOUGH TO DEAL WITH HAVING LUNG CANCER, UNDERGOING CHEMOTHERAPY, NOW THERE IS THIS OTHER THREAT LOOMING THAT SEEMS SO DANGEROUS. I SAW PATIENTS DECIDING HOW THEY WANT TO SPEND WHAT MAY BE THE LAST YEAR OF THEIR LIFE, DECIDING IF THEY SHOULD SHELTER FROM COVID OR SEE LOVED ONES.”

DR. NORMAND BLAIS, MEDICAL ONCOLOGIST, MONTREAL

Losing the support of loved ones

During COVID-era restrictions at hospitals, the experience for lung cancer patients attending appointments as well as those staying as inpatients dramatically changed. As a result, isolation became a greater threat.

Patients found themselves having to attend hospitals or cancer centres alone, without family members, due to restrictions. “You could feel their distress,” said Dr. Blais. “They were alone, worried, stuck in their ideas, unable to understand the discussion we are having with them.”

In the Lung Cancer Canada survey, nearly 60 per cent of patients reported not being permitted to have caregivers join them at appointments.

The cascading effects included feeling a lack of emotional support (58 per cent), increased fear/stress (39 per cent) and greater vulnerability (38 per cent).

Andrea Redway was diagnosed six years ago with stage four lung cancer in Ottawa. She started her second round of immunotherapy in winter 2021. Andrea said the stakes are high in treatment and having support is invaluable.

“It makes a huge difference when you don’t have a caregiver to accompany you,” Andrea says. “They get you through the worst times of your treatment. That kind of emotional support is critical to helping people deal with anxiety, navigate the ups and downs, and maintain the courage to keep going.”

A caregiver also helps digest and remember the health-care team’s instructions. Many survey respondents noted having a hard time remembering information after

attending an appointment solo, feeling “very lonely and uncertain” without that second set of ears, and have a sense of being lost without that prime caregiver by their side.

Andrea says that when she was first diagnosed and entered the oncology department, she was in shock and very ill and she needed someone to be with her to listen and understand. “It’s my husband who understands the full context, who does all the research before going, who asks the questions,” she says. “Newly diagnosed patients are not generally in a strong place mentally during appointments to interpret or clarify.”

Angus Pratt, in Surrey, B.C., was diagnosed with stage four lung cancer three years ago and is currently stable taking targeted therapy. He said that during his first chemotherapy treatment before COVID, he found the physical presence of his caregiver to be comforting as the medication took effect. The second round of immunotherapy infusions, however, was different.

“My caregiver couldn’t come with me during immunotherapy, so I ended up sitting next to the same person every two weeks,” he says. “We actually ended up developing a strong friendship and he wound up breaking privacy rules to get my phone number to keep in touch.

“That’s special, and unique because I think for men it’s challenging. We are soloists. We think we’ll be fine, but really, we need that support.”



Andrea Redway

Being alone, at the end

“Not being able to visit my wife when she passed in the hospital is really indescribable, from an emotional perspective. I’ve had to drive it from my mind.”

That gutting observation from one of our survey respondents reflects what is without question the most tragic, intimate consequence of COVID’s impact on lung cancer patients.

Across Canada, to varying degrees depending on provincial lockdowns, an unknown but significant number of people were being admitted to hospital for the last time. They would die there of their lung cancer, without loved ones by their side.

“A lot of our lung cancer patients didn’t get better and in fact many died alone,” says Dr. Snow. “Some patients chose to stay home at their end of life, because they didn’t want to be separated from their loved ones. On medical oncology floors, people were admitted for end-of-life care and they couldn’t have their people with them. And that was heartbreaking.”

“NOT BEING ABLE TO VISIT MY WIFE WHEN SHE PASSED IN THE HOSPITAL IS REALLY INDESCRIBABLE, FROM AN EMOTIONAL PERSPECTIVE. I’VE HAD TO DRIVE IT FROM MY MIND.”

SURVEY RESPONDER

SUPPORT FOR FAMILIES IN END-OF-LIFE CARE

For those families who were able to be together with their loved ones near the end, another issue was laid bare: the fact that many are uninformed about what dying actually looks or feels like.

Often described as “fading” – when a patient becomes tired and weaker, it can creep up suddenly over the months, weeks, and finally days, as even simple daily tasks become too much to manage.

Yet many families don’t know what to expect when end-of-life becomes a reality for their loved one. These concerns were magnified during COVID, when the choice of whether to stay home or go to the hospital could mean the last time they’d see their brother, mother, or child.

For Christa, that loved one was her brother-in-law who, toward the end of his journey with lung cancer, had trouble catching his breath while walking or caring for his dogs. Despite the limitations of COVID, Christa reached out to learn what the last days look like. She got in touch with Dr. Samantha Winemaker, who was able to help Christa feel that it was okay to speak about death. Dr. Winemaker helped Christa feel less fear and acknowledge the need for comfort in the last days of life. She says knowing what to expect helped her ready herself for the inevitable. Her story was captured in this [Waiting Room Revolution podcast](#).

A SENSE OF LOST TIME AND FREEDOM

In some ways, this pandemic impacted the lives of Canadians with lung cancer in less tangible yet very meaningful ways.

Already, quality of life is known to be lower in this patient group than in the healthy population, as well as patients suffering from other malignancies – as detailed throughout scientific literature including this [2016 study](#). We also know that self-assessed quality of life scores influence each person's outcome and survival.

Factors that impact quality of life include such key dimensions as physical, psychological, cognitive, social, and life roles. Many are already unable, or have a limited ability, to play their important family and social roles as a result of the disease – and COVID-19 extended these challenges.

The pandemic served to diminish the sense of freedom and control that lung cancer patients and their loved ones had over their lives. We can say that these are temporary losses, but a pandemic that is expected to last as long as three years is a long window for people with a disease whose five-year net survival rate is [19 per cent](#).

Dr. Rosalyn Juergens, medical oncologist in Hamilton, Ont., says that she misses the challenge of trying to figure out how to integrate cancer care around patients who are still well enough to live their lives and take advantage of the world around them.

“I actually miss, for instance, having to coordinate a patient's immunotherapy appointments around their summer schedule,” Dr. Juergens says. “We are buying patients time, and during the pandemic, they are missing these critical opportunities to do a family trip, to create memories, to be with loved ones, and I can't wait to get back to those scheduling challenges so that our patients can get back to living their lives despite having lung cancer.”

There was a creeping sense of loss during COVID, among lung cancer patients. In Winnipeg, Christine Wu was diagnosed five years ago – a turn of events that her daughter Parisa says strips away one's sense of control over your own body, your own future, and what you can and cannot do.

“COVID made that feeling so much worse, with the feeling that the entire world has now lost control, including the health-care teams you had relied on,” Parisa says.

“In watching my mother, I would just say that it's imperative that, as society opens up after the pandemic, that we give people with lung cancer choices to restore that sense of control over their lives. Even giving them simple choices, like if they'd prefer a Zoom call or an in-person appointment, restores that vital feeling of control, which is so important to their mental health and well-being – especially during these hard times.”

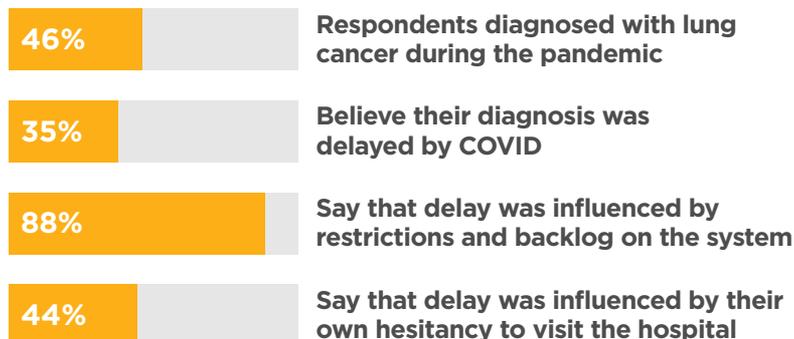
“WE ARE BUYING PATIENTS TIME, AND DURING THE PANDEMIC, THEY ARE MISSING THESE CRITICAL OPPORTUNITIES TO DO A FAMILY TRIP, TO CREATE MEMORIES, TO BE WITH LOVED ONES, AND I CAN'T WAIT TO GET BACK TO THOSE SCHEDULING CHALLENGES SO THAT OUR PATIENTS CAN GET BACK TO LIVING THEIR LIVES DESPITE HAVING LUNG CANCER.”

DR. ROSALYN JUERGENS, MEDICAL ONCOLOGIST, HAMILTON, ONTARIO

PATIENT EXPERIENCES DURING COVID-19

In spring 2021, Lung Cancer Canada commissioned a survey of Canadians with lung cancer to help understand their perspectives, concerns, and experiences during the pandemic. Here are key statistics from that survey that help tell the story.

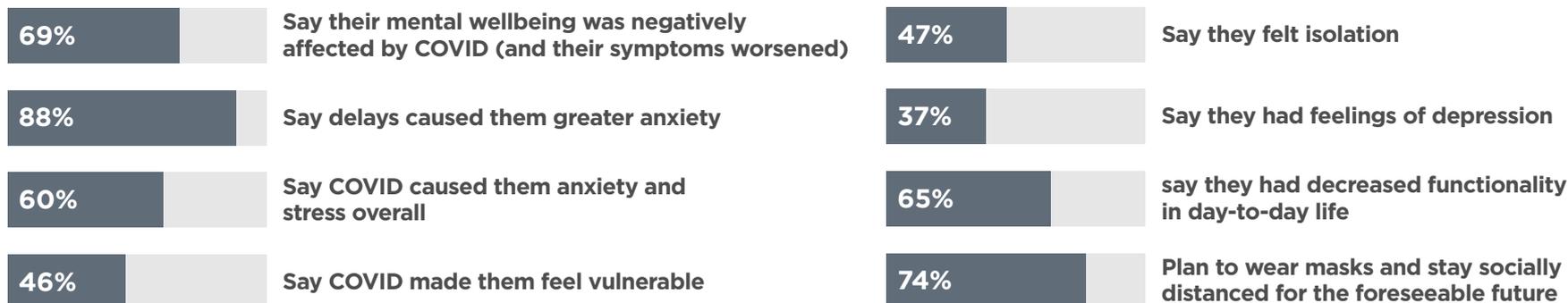
DIAGNOSIS



CARE



MENTAL HEALTH



ACCESS TO COVID VACCINES

The swift arrival of multiple vaccines for a new virus will be viewed in history books as remarkable. It represents a major turning point in science, and bodes well for future health threats.

Still, lung cancer patients already under stress had to contend with how to navigate a rocky vaccine rollout. Andrea Redway, an Ottawa resident with lung cancer, says that the pandemic highlighted the inconsistency in care across Canada.

“The vaccine rollout was so different in each province and, although we all got both doses eventually, the timing and pace of them was all over the map,” she says. “That echoes the challenge I see with our health-care systems overall in terms of how treatments and testing isn’t equitable across the country.”

The lung cancer community is well-connected, and those connections transcend boundaries and borders – so in spring 2021 when vaccines became available, people were acutely aware of priority groups from province to province and anxiously awaited the rollout in their cities and towns.

When it came to vaccine timing for lung cancer patients, some provinces had clear plans, while others stoked confusion over priority cohorts and what defined “immunocompromised.” In the end, two Canadians with the same diagnosis faced a different vaccination path if they lived in separate provinces.

Elya Martinson, a patient whose story is featured in this report, has been an advocate for a more precision rollout of the vaccine for lung cancer patients in British Columbia.

She says that for the first vaccine, people with solid cell cancers were prioritized and she was able to get vaccinated on April 14, 2021. That wasn’t the case for her second vaccine that she wound up receiving later than the recommended time period.

Second dose needed in weeks, not months

“The pandemic has been rough, and the vaccine rollout was difficult to watch,” says Elya, a single mother of three. “I couldn’t risk getting COVID in my already scarred lungs. I needed the vaccine, and my kids needed it too, to finally have some kind of peace.

“They put aside their lives, their friends to bubble with me, and that’s hard for teenagers. They should be able to go for a bike ride with friends outside. I was so desperate to get vaccinated – not as much for me, as for them.”

Dr. Wheatley-Price says this is a key point – because research showed at the time that cancer patients were not achieving the same level of immunity as healthy individuals from the first dose.

“They needed that second dose after three or four weeks, not three to four months,” he says. “And if you had to wait too long, as many people did, it risked being less effective.”

Indeed, U.K. researchers tracked the immune response of 151 cancer patients to a single Pfizer BioNTech vaccine. They found, after three weeks, the immune response of people with solid cancer was 38 per cent, and just 18 per cent in those with blood cancer. These numbers paled to the 98 per cent efficacy rates among cancer-free individuals. They also found the immunity response improved among cancer patients when they got their second shot three weeks after the first. Researchers [published](#) these findings last spring in *The Lancet*.

The study, while small, transformed Elya from patient to [advocate](#), urging the government on behalf of her lung cancer patient community to expedite the second vaccine. While some provinces, including Ontario and Alberta, shortened the period of time for some cancer patients, B.C. had kept the four-month gap as they tried to get as many first doses out as possible.

“It was very disappointing because I would hear from healthy people that they got their second vaccine and I still had not, despite it being so crucial for cancer patients,” Elya says.

ELYA MARTINSON Kelowna, B.C

Diagnosed During COVID-19

After being diagnosed with lung cancer at the same time as a pandemic locked down the country, Elya Martinson, a single mother of three in Kelowna B.C., was determined not to be simply a survivor of lung cancer but a *thriver*.

The 36-year-old returned to university to study for a master's degree in social work in September 2019. She kept a primarily plant-based diet, worked out regularly, and never smoked. On the last day of April 2020, just days after writing her final exams, Elya received the shock of her life: she had advanced lung cancer – adenocarcinoma.

The road to this life-changing diagnosis was, as is the case for too many Canadians, not a smooth one.

“I could sense the cancer progressing”
– Elya Martinson

Elya had been experiencing pressure in her chest for a couple of months, but had chalked it up to the stress of school, a recent divorce, and the challenges of single parenthood. “At night time I was uncomfortable and had to sleep on my side,” says Elya. “It felt like someone was squeezing my chest.”

Eventually she called her doctor, who asked her to call back in two weeks if it was still bothering her. There was no improvement, so she called again. This time, she was sent for a chest X-ray.

“When the radiologist reviewed it, I was told to go to the ER immediately – in fact I was wheeled there,” says Elya. “The doctor told me my right lung was three-quarters full of fluid and was surprised I could walk and talk normally.”

Because she didn't smoke, doctors first assumed it was pneumonia, so Elya was admitted to drain the fluid. But when the lung didn't drain days later, doctors ordered more tests.

“Just before I was diagnosed I was saying, well, everything seems to be falling apart around me, but at least I have my health,” says Elya. “Then about a week later, I got a phone call with the diagnosis.”

From the fluid samples, doctors found malignant cells. “It was absolutely traumatizing to be diagnosed with stage 4 lung cancer when I was at home with my kids,” says Elya. “I was given a two or three year prognosis.”

Her cancer was advancing fast and Elya says that she felt worse with each passing day. “I could actually sense the cancer progressing into my lymphatic system,” she says. “I could feel the nodes in my neck, armpits and knees growing.”

It took over a month from that phone call to be seen at the cancer centre and begin treatment – weeks that Elya and her family found unbearable due to the uncertainty. By the time she got to the centre, she couldn't talk without breaking into coughing fits.



Elya Martinson

Her oncologist recognized her need for a PleurX catheter and put her on osimertinib, which prompted the fluid to finally drain, despite some difficult side effects.

Thriving through the storms

In the face of her new reality, Elya credits her amazing family with giving her the support and strength to try and thrive through the “storms” of lung cancer. “Some days are worse than others, when the waves are impossibly high,” she said.

In Elya's house today there are crafts and signs and knickknacks displaying the word “joy,” many of which were delivered by friends and family. She wanted to fill her home with as much positivity as she could – and that word “joy” is far more than a kitschy slogan.

“My middle name is Joy,” she says. “I think my mom named me that knowing that at some point in the future, I'd have to find that inner joy. It's giving me the strength to call myself a thriver.”

In short order, Elya has become an outspoken advocate for erasing stigma surrounding lung cancer. “Anyone can get it, and it really bothers me that when people heard that I had it, they asked if I smoked. I didn't, but who cares if I did or not? We need to change the script and ask helpful questions. How are you feeling? How can I help? Those are questions that can help people living through lung cancer.”

Hear Elya detail her story in this [Lung Cancer Voices](#) podcast.



PART 2

SPOTLIGHT: RISE OF VIRTUAL CARE

A SUDDEN SHIFT BRINGS NEW OPPORTUNITY

Virtual care was still in its infancy in early 2020 but, over the following year-and-a-half, it quickly became a necessary mode of care. In order to stop the spread of COVID, telehealth appointments swiftly became the norm for checkups while videoconferencing platforms were widely adopted.

A spring 2021 [survey](#) of 2,000 physicians – from GPs to specialists – by the Canadian Medical Association and Canada Health Infoway found that 94 per cent now use virtual care with patients. The vast majority offer telephone visits while just over half offer video visits. Seven out of 10 said virtual care enabled better access to more efficient care – and the same number said they are equipped to make virtual care a mainstay moving forward.

CMA president Dr. Ann Collins told [CTV News](#) in August 2021: “What’s become evident is that there’s a great deal of benefit to virtual appointments. We’re not going back to where we were in March 2020.”

The rise of virtual care carries many positive results, though it’s important to remember that lung cancer management is complex and individual. Virtual care became part of care strategies during COVID across Canada, to mixed results. In interviews with oncologists and patients for this report, this was a preeminent subject of conversation. Here’s a look at what happened in virtual lung cancer care during the pandemic, and learnings for the future.



Bev Moir

BENEFICIAL WHEN USED APPROPRIATELY...

Tele- and video visits enabled newfound accessibility for Canadians in any community to conduct appointments with their health-care teams from afar, saving often significant travel time.

Dr. Stephanie Snow, oncologist at QEII Health Sciences Centre in Nova Scotia, says that virtual care can be used appropriately for those patients who can be assessed properly at a distance.

“For many rural patients, providing care in their home is better than driving five hours to Halifax, especially those who are stable on oral therapies,” Dr. Snow says. “COVID has in some ways empowered a new opportunity to provide patients with resources in a different way.”

Bonnie Leung, nurse practitioner at BC Cancer Agency, expects there to be a component of telehealth moving forward, from both logistical and therapeutic standpoints. “Cancer centres have a lack of space, so to be able to perform clinics over the phone alleviates some pressure,” says Leung, adding that the Agency has now developed an office of virtual health.

Dr. Paul Wheatley-Price in Ottawa says it’s liberating for patients many hours away to have remote appointments, and that COVID demonstrated that things can evolve, in a hurry. “In the past, it would take years of committee meetings and bureaucracy to implement virtual care, but provinces quickly allowed billing practices to evolve with virtual care, and that’s a good thing.”

In Montreal, Dr. Normand Blais agrees that permanent, Canada-wide tele-health billing practices will be critical to virtual care’s staying power in lung cancer. While Dr. Blais prefers in-person patient visits, he does acknowledge how virtual care could work.

“If I can see more patients in one day who need care, then that is a clear benefit for them,” he says. “I could then determine week to week which patients I’m comfortable speaking with over the phone or on video, and which I need to see in person.”

Dr. Rosalyn Juergens in Hamilton, Ontario says that virtual care has a place in lung cancer, but the right rapport must be struck with patients.

“With each patient, I make a bit of a deal,” Dr. Juergens says. “Once I’m confident they are on the right path, we can integrate virtual care. They come to clinic, do bloodwork, go home and I’ll call for a virtual follow-up if all is well. But they have to promise that if something has significantly changed, they must stay for an in-person assessment so we can address their new symptoms quickly. That’s the healthy approach.”

...But no substitute for in-person care

Virtual care nonetheless brought difficulties in how practitioners could administer quality lung cancer care over phone or video.

In fall 2020, Dr. Snow saw a patient (lifelong non-smoker) who presented with skin metastases on her abdomen. In person, she didn't have to touch the large, hard lump to know immediately that it was cancerous. But for months the patient had been treated via tele-medicine with family physicians who assessed it from afar, presuming it was a routine cyst. The woman was referred to a dermatologist to drain the cyst and, at that point, they suspected possible cancer. The dermatologist performed a biopsy, which revealed that she has metastatic lung cancer that had spread, including to her brain.

"I'm treating her now, because she will receive benefits from the treatment, but I wondered how much different her condition would have been if we'd diagnosed it months earlier," Dr. Snow says.

There is, all oncologists interviewed for this report agree, no substitute for being able to assess a lung cancer patient in person. Effective, personalized care requires a Gestalt approach of actually seeing a patient – listening to their lungs, examining them and feeling something unexpected, or seeing how frail someone actually is in the moment. Oncologists and their teams get to know patients personally, what their body feels like and lungs sound like, so that they can instinctively tell when their condition is deteriorating.

During COVID, Dr. Snow found herself doing a lot of telephone medicine with elderly patients isolating at home, uncomfortable with video. "There's an art to what we do, and over the phone that art is lost," she says.

According to her, some anxious patients don't want to risk disrupting their therapy or care plan, and as a result may explain over the phone that they are

well but in reality are not. They may say their appetite is fine – but in person, a scale reveals them losing several kilograms in the past month. Objective information, like weight, oxygen saturation, how quickly a patient can walk down the hallway, and how they actually look, is essential to providing quality care – yet it's difficult to obtain virtually.

"What's more is that there are delicate, personal conversations I have with patients that just don't translate over the phone or on a screen," she says. "It's not the venue to give them difficult news, and it's impossible for my nurse to go and give them a hug."

In Edmonton, Dr. Quincy Chu considers virtual care a difficult avenue of care. "From the waiting room to the clinic room is a 20-metre walk, and I'll know a patient's actual status in part based on that walk," Dr. Chu says. "I can't tell that online because I can't properly assess them and thus can't easily identify patients who are sicker than they should be."

“WHAT’S MORE IS THAT THERE ARE DELICATE, PERSONAL CONVERSATIONS I HAVE WITH PATIENTS THAT JUST DON’T TRANSLATE OVER THE PHONE OR ON A SCREEN...IT’S NOT THE VENUE TO GIVE THEM DIFFICULT NEWS, AND IT’S IMPOSSIBLE FOR MY NURSE TO GO AND GIVE THEM A HUG”

DR. STEPHANIE SNOW, MEDICAL ONCOLOGIST, NOVA SCOTIA

Virtual care: onerous, often ineffective

Dr. Rosalyn Juergens says some patients are caught in an unhealthy part of virtual care – because they are paralyzed by fear of COVID. She didn't see one such patient for 15 months, who was content on taking oral therapy at home, refusing to step foot in the hospital.

"Virtual care is not possible for some patients, because many details get lost over the phone," Dr. Juergens says. "Most importantly, virtual care should be used when it's the right clinical approach, but not because a patient is afraid to come in person. I don't want patients to be frightened to seek health care."

While telehealth is convenient, it is onerous on health-care teams. It can easily slow the pace of care, as it takes longer for providers to get the information they need. In Montreal, Dr. Normand Blais says finding the right phone number, getting answering machines, and waiting for sick patients to get to the phone are minor issues that become major when telephone visits are frequent. Video appointments are delayed by connection issues or older patients needing time to get comfortable with the technology. Backlogs result.

"I honestly think to make virtual care work properly, hospitals would have to hire teams of IT specialists to support a reliable system," Dr. Blais says.

Dr. Chu considers virtual care time consuming and potentially less efficient. "In many cases virtual care doubles my workload as I must ask far more questions than if I saw a patient in-person," he says. "I lose the ability to have nurses brief me, a crucial pre-assessment not available virtually. I often spend more time convincing a patient to come in, than managing their status."

Dr. Paul Wheatley-Price says that while there are plenty of reasons to embrace virtual care, the problem is that lung cancer patients often have fluctuating symptom scores, are sick, and have other health issues – all of which need the in-person touch. He is uncomfortable prescribing any new course of treatment without having seen someone in person. And sometimes a phone appointment necessitates a subsequent in-person appointment – thus doubling the time.

He recalls one story that demonstrated the limits of virtual care and the rise of double-appointments. "It was a consult about chemotherapy for a patient who'd just had a difficult time with surgery and whose first language wasn't English," Dr. Wheatley-Price says.

"He sounded very sick so I arranged to see him two days later. But it turns out, he just had a normal, gravelly voice. But on the phone, the way he sounded and the language barrier meant I would have interpreted his status far differently. The in-person visit was necessary. He received a course of chemotherapy without any complications, and is doing well."

"IN MANY CASES VIRTUAL CARE DOUBLES MY WORKLOAD AS I MUST ASK FAR MORE QUESTIONS THAN IF I SAW A PATIENT IN-PERSON...I LOSE THE ABILITY TO HAVE NURSES BRIEF ME, A CRUCIAL PRE-ASSESSMENT NOT AVAILABLE VIRTUALLY. I OFTEN SPEND MORE TIME CONVINCING A PATIENT TO COME IN, THAN MANAGING THEIR STATUS."

DR. QUINCY CHU, MEDICAL ONCOLOGIST, CROSS CANCER INSTITUTE

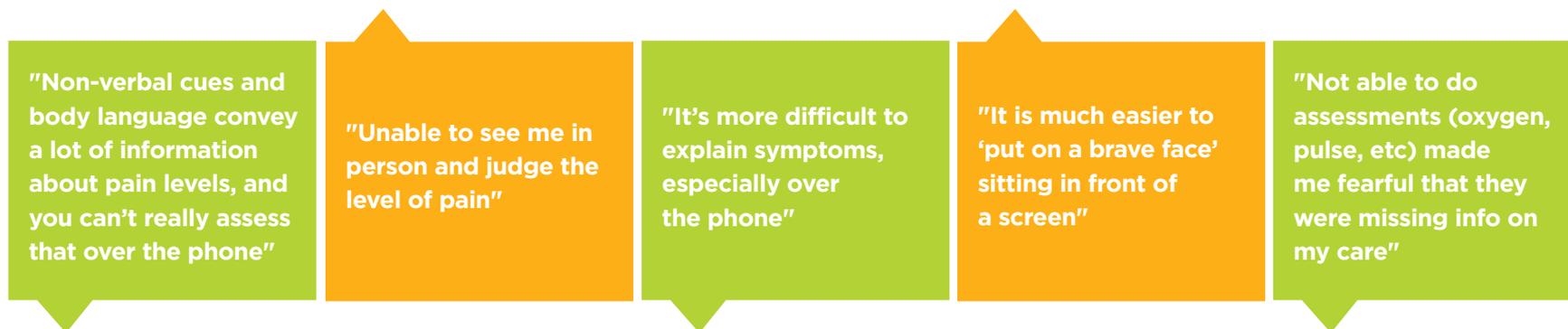
WHAT DO PATIENTS SAY ABOUT VIRTUAL CARE?

According to our 2021 patient survey, 95 per cent of respondents had virtual appointments during the pandemic – predominantly over the phone. Respondents were also evenly split about how they felt about virtual appointments – with 38 per cent finding it comparable to in-person care and 37 per cent finding it ineffective.

Patients surveyed highlighted three key benefits of virtual care: lack of travel (87 per cent); easier access to care (63 per cent); and being able to be in a comfortable environment (61 per cent). One respondent wrote: “It allowed

me to work/do other things right up until I received my call, no more endless hours sitting in a hospital. This means more than you can imagine to people whose time is ‘ticking’.”

Still, the survey illustrated clear drawbacks in receiving lung cancer care virtually. Seven out of 10 said it was less personal, they felt less supported, and most said that not having a physical exam made them feel like key parts of care were being missed. Here are several comments from the survey:



94%

DESIRED IN-PERSON CARE FOR INITIAL DIAGNOSIS

86%

DESIRED IN-PERSON CARE IF THEIR DISEASE IS PROGRESSING

70%

“VERY COMFORTABLE” RETURNING TO IN-PERSON VISITS, IN SPRING 2021

25%

DON’T PREFER VIRTUAL CARE UNDER ANY CIRCUMSTANCE

Virtual care: good in the right context

For Canadians with lung cancer, alternate approaches to care are valuable. Yet the patients interviewed for this report say that it should be used in measured ways, in consultation with patients themselves.

“Virtual care is great as long as it’s used in the right context,” says Andrea Redway in Ottawa.

“Virtual appointments for routine matters can save us a ton of time and expense, but if you’re really battling symptoms and things feel off, you have to be seen in person and assessed by your doctor.”

Angus Pratt in Surrey, B.C. agrees that there are positive elements of virtual care, for more straightforward check-ups. “I think the genie is out of the bottle now, and my physicians can bill for a phone call – it’s the way it should have been from the get-go,” he says.

One key point patients highlighted when it comes

to virtual care is that we must not forget the loved ones, the family members, the community of support that surrounds each patient. They are impacted by lung cancer themselves and deserve to be part of the care plan – and, of course, they are the ones often holding patients upright in navigating the health-care system.

Don’t forget the caregivers

“It’s critical that in balancing virtual care with in-person, we think of the role of the caregiver in providing emotional support and informational support,” Andrea says. “I couldn’t do much more than get myself to appointments for a while – without my husband being there and staying informed, I would be lost.”

Parisa Sepehri’s mother Christine has lived with lung cancer for five years. Parisa says if done right, virtual care can create more opportunities for busy family members to support their loved ones.

“I may not be able to attend an oncology visit that

is a three-hour outing,” Parisa says, “but I could attend a one-hour Zoom meeting with my mom.”

Heather Hogan lives in Woodstock, N.B. and was diagnosed with stage 3A non-small cell lung cancer in 2012. She says that virtual appointments are valuable to Canadians like her, who live in rural communities, but that it can easily run the risk of patients feeling isolated and stressed.

“A lot of lung cancer patients don’t ask questions of doctors about their upcoming journey, treatment plan, expectations and other details that would help them feel more engaged and empowered,” Heather says. “We must ensure with virtual care that patients get the support they need in those moments.

“On Zoom calls with my oncologist I need my husband there listening for me and asking questions. But some patients, perhaps they live alone, may not have that support and that help in interpreting information. Virtual care can heighten isolation in those cases.”

LUNG CANCER CANADA BELIEVES

- Decisions around virtual care must be made in consultation with patients. Medical care is a relationship of mutual consent, and any decisions around mode of care must consider the preferences and needs of the individual patient.
- Care providers must be empowered to integrate virtual care into their practices in a manner that respects this patient relationship, as well as their own time and resource needs and constraints.
- The role of the caregiver must be considered in terms of emotional and informational support when balancing the merits of virtual vs. in-person care.
- In general, the limits of virtual care outweigh the benefits and decisions on care should reflect that imbalance.



PART 3

IMPACT ON PROVIDERS

SNAPSHOT

Nowhere in Canada was the pandemic more disruptive and consequential than inside medical clinics. These clinical teams, in every field of medicine, bore the greatest brunt of COVID-19 while they maintained continuity of care for their patients to the best of their ability.

For lung cancer care providers, it brought major challenges in staying on top of their patient loads and deliver the personalized, often nuanced care needed for these vulnerable Canadians.

In this section, providers we spoke with detailed widespread professional burnout, the sudden need to navigate deep systemic delays, stalled or missed clinical trials, and a loss of team. (The subject of virtual care, a key point of emphasis, is reported independently in part two of this report.) Of course, all difficulties faced by practitioners have direct implications on lung cancer patients, and their health outcomes.

In a *British Medical Journal* [article](#) from spring 2021, authors noted that the pandemic forced oncologists to determine how and if to modify, delay or cancel some treatments for lung cancer patients. Moving forward with chemotherapy, immunotherapy and targeted treatments did have some risk factors in the context of COVID – but how were they to be balanced with negative impacts of delaying cancer care? While some international consortiums tried to bring recommendations and help mitigate the resulting COVID

crisis on cancer care – it was still, by all accounts, a pandemic of dilemmas for each practitioner on the ground.

Such decision making was made more difficult amidst an environment of shifting mandates and regulations, reallocated staff to the COVID front-lines, reduced resources, and patients who were gripped with anxiety about visiting a hospital. Lung Cancer Canada could relate much of the on-the-ground impact detailed by oncologists as trying to plug leaks on one side of a boat while others spring up elsewhere.

“The onus can’t be on oncologists alone to shoulder the burden of patient care,” says Dr. Normand Blais, “and to overcome gaps and deficiencies in the system.”

Even while grappling with COVID’s impact, Dr. Stephanie Snow was concerned about the coming impact on health-care budgets. Some of the priorities in lung cancer, such as promoting coverage of oral therapies and extending screening, take considerable funding.

“This means our top priorities pre-COVID are going to drop even lower down the priority list for governments who are just reeling from the economic fallout,” Dr. Snow says. “I worry about our government’s ability to even sustain the improvements we’ve made, which are critical to providing the best care for our lung cancer patients.”

PHYSICIAN BURNOUT

Long before the pandemic took hold, Canadian physicians were experiencing symptoms of burnout – a condition marked by physical and emotional exhaustion, cynicism and low sense of professional accomplishment. A [2018 survey](#) by the Canadian Medical Association found that 30 per cent of physicians experienced burnout and 33 per cent experienced depression. Similar findings have been found last decade in the U.S. and around the world.

In 2016, the American Society of Clinical Oncology published a [paper](#) on burnout among these oncologists, noting that their roles bring “exceedingly long hours, in direct care with seriously ill patients/families, limited autonomy over daily responsibilities, endless electronic documentation, and a shifting medical landscape.” Moreover, a burnt out cancer care clinician impacts quality of care and patient satisfaction.

A [March 2020 piece](#) in the *New England Journal of Medicine* labelled physician burnout a “crisis” simmering for years, ignited now by the emergence of data science and performance metrics.

“Then COVID strikes,” says Dr. Paul Wheatley-Price, “and our medical community brushed that aside as physicians banded together in an altruistic fashion. But as the pandemic continues to drag on, and the pressures on health-care providers persist, the pre-COVID issues are back on the table again and unfortunately we are seeing burnout more and more amongst ourselves and our colleagues.”

In the pandemic’s preliminary phases, oncologists worked tirelessly to put patients first even as the pace of care ratcheted up. Dr. Quincy Chu says

that staff tried to get things done as quickly as possible because they didn’t know if they could do what they needed to do the next day, as the pandemic unfolded.

A year-and-a-half later, Dr. Chu says that he feels colleagues are experiencing the toll that the pandemic took on care teams.

“Some are on sick leave, and I’m concerned that skilled clinicians will move out of oncology because the workload feels insurmountable,” he says. “We can’t accommodate patients the way we’d like, as the phone is ringing off the hook with worried patients but we have to tell them they have to wait for their appointment because we have no capacity.”

Dr. Normand Blais echoes the sentiment that staff are having a hard time staying at a high level after months within a pandemic. “We’ve suffered from high anxiety, poor sleep, and overwork,” he says. “Everyone has been performing at a high level during COVID, doing the best they can to compensate for deficiencies in the system. It was very difficult for a while.”

Dr. Stephanie Snow witnessed burnout among care teams in Halifax, and people struggling to cope with the longer hours and a more difficult job amid greater isolation.

“For our nurses, I saw the realities of the pandemic weigh heavily, and we saw a lot leave oncology,” Dr. Snow says. “One veteran nurse took a leave of absence because she was struggling with her mental health and knew she couldn’t give our patients what they deserved.”

Consequences of physician burnout

The oncology community is in a process of reconstruction, of cutting into the deep backlog of surgeries, and of setting systems of care back upright. It has been, for most of COVID, simply survival mode. But this is an exhausted group of professionals, and oncologists across Canada are worried about their staff's wellness long into the wake of COVID.

"I can't honestly tell our patients that they have the best quality of care right now," says Dr. Normand Blais. "Before COVID the system had some holes, it was imperfect care. But right now we are much lower than we were then."

Dr. Rosalyn Juergens echoes that sentiment in her concern over the risk that oncologists are unable to provide care to the best of their abilities. Most aim to go each extra mile needed: applying for medications that aren't yet approved, or referring and enrolling patients to clinical trials to access the treatment they need, arranging for molecular testing so patients have all opportunities on the table to manage their disease.

"Our patients deserve personalized care, the latest treatments, and physicians who aren't burnt out," Dr. Juergens says. "I miss the ability to provide interdisciplinary care and I miss the connections with nurses and other care providers, as well as patients and their families. During COVID, oncologists experienced both burnout and loss."

She adds that because of the additional roles and time-consuming work caused by the pandemic, providing her "best self" to patients every day has caused her to miss personal events, like her son's first baseball game. The professional burnout, in that way, leaks into an oncologist's family life.

Dr. Snow is acutely concerned about the long-term consequences of burnout, particularly among nurses and other care providers who play critical roles in serving lung cancer patients.

"We've seen COVID-related burnout expedite retirements and cause nurses to seek roles in different departments – and they may not return," Dr. Snow says. "We can hire great new people, but in the near term we lose the experience and the insights. You can't easily replace 30 years of working with cancer patients. And at the same time, new staff lack the mentors they need to succeed."

“OUR PATIENTS DESERVE PERSONALIZED CARE, THE LATEST TREATMENTS, AND PHYSICIANS WHO AREN’T BURNT OUT...I MISS THE ABILITY TO PROVIDE INTERDISCIPLINARY CARE AND I MISS THE CONNECTIONS WITH NURSES AND OTHER CARE PROVIDERS, AS WELL AS PATIENTS AND THEIR FAMILIES. DURING COVID, ONCOLOGISTS EXPERIENCED BOTH BURNOUT AND LOSS.”

DR. ROSALYN JUERGENS, MEDICAL ONCOLOGIST, HAMILTON, ONTARIO

DELAYS IN THE SYSTEM

From the start of a patient's journey...

The beginning of a lung cancer patient's journey begins pre-diagnosis – in most cases via a trip to emergency when someone feels unusually sick, or via a family physician who is concerned about symptoms. During COVID, in both scenarios, there were delays – meaning critical delays to diagnosis.

“Even without a pandemic, patients often are reluctant to get something checked, scared of having their worst fears confirmed,” says Andrea Redway, a lung cancer patient in Ottawa. “COVID only served to delay things more, which is a disaster for this disease that can become incurable.”

On one hand, anxious Canadians were extremely hesitant to visit the emergency department for fear of COVID that paralyzed communities. (This is detailed in part one of this report.) On the other hand, appointments with family physicians were harder to make as operations shifted virtual and at the same time less effective at spotting early warning signs for lung cancer. Those family doctor appointments are vital in setting up someone's diagnostic pathway.

“Doctors tend to have shorter patient dialogues over the phone than in person, which means that if the patient doesn't bring something up, it may be missed,” says Dr. Normand Blais, who says picking up subtleties in tele-consultations is difficult. “Then the appointment is over, and someone doesn't book another appointment for two months.”

Another problem is that outside of populated areas of Canada, there tends to be a shortage of family physicians. A 2019 Stats Can report showed that 14.5 per cent of Canadians didn't have a primary care practitioner. Three provinces exceeded that rate – Quebec, Saskatchewan and B.C. The biggest reasons reported were that there simply wasn't one in the nearby community, or that a doctor retired or moved.

These are broad numbers, but on a local level they can become more stark. Dr. Stephanie Snow says that in Atlantic Canada, about half of residents in some counties have no family doctor. As a result, undiagnosed lung cancer patients present much of the time to the emergency department – and, in fact, wait much longer to do so during a pandemic.

A common occurrence is that someone visits the ER after weeks or months with a progressive cough and shortness of breath, determined by the attending physician to have pneumonia and given antibiotics. “When they don't get better, they return to the ER and get a CT scan, and are finally referred to a thoracic surgeon, at which point things escalate,” Dr. Snow says.

“But it's those steps around emergency, and the follow-up cascade, when patients believe they have the drugs to treat pneumonia and they go about their days, when crucial time is lost. This was already happening – and COVID made these delays worse.”

What's more is that, with COVID-19 top of mind everywhere, it, along with pneumonia, may be presumed first, before lung cancer becomes a consideration in overrun hospital emergency departments.

“Lung cancer symptoms are so similar to the presenting symptoms of COVID – and there is stigma to both in terms of diagnosis,” says Dr. Juergens. “This has all doubly affected people's ability to present in a timely fashion.”

... to the critical scanning and treatment phases

During the pandemic, Dr. Blais describes as a “nightmare” the delays in accessing scans, biopsies and pathology reports once a potential problem has been recognized. Radiology was slowed by COVID protocols around equipment, and biopsies slowed by staffing issues and shortages.

“Nowadays, patients will have a three to nine month delay before accessing treatment,” Dr. Blais says. “In many cases, a preliminary scan is clear, and then my patient waits for PET scans and biopsies, waiting to get to the next level of specialty. Five months later, they can begin treatment – if they are still well enough to do so.”

Dr. Wheatley-Price agrees that there is considerable concern about potential delays making a lung cancer diagnosis. This varied depending on region, but potential delays include initial access to a family doctor, accessing specialists in a timely fashion, delayed diagnostic tests due to staff levels and COVID precautions around rooms and equipment grinding down the pace of care. At the most drastic level, there were contingencies and algorithms developed to prioritize patients for treatment, which fortunately didn't need to be used, but even they brought other issues to the forefront.

“This put a kind of moral stress on clinicians about what to do if we have to prioritize certain patients,” he says. “In the ICU, physicians had to decide who got a ventilator and who did not. At one point we were potentially saying to one patient ‘you can have treatment today’ while saying to another ‘you can’t.’ That is not what we went into medicine to do.”

“THIS PUT A KIND OF MORAL STRESS ON CLINICIANS ABOUT WHAT TO DO IF WE HAVE TO PRIORITIZE CERTAIN PATIENTS,” HE SAYS. “IN THE ICU, PHYSICIANS HAD TO DECIDE WHO GOT A VENTILATOR AND WHO DID NOT. AT ONE POINT WE WERE POTENTIALLY SAYING TO ONE PATIENT ‘YOU CAN HAVE TREATMENT TODAY’ WHILE SAYING TO ANOTHER ‘YOU CAN’T.’ THAT IS NOT WHAT WE WENT INTO MEDICINE TO DO.”

DR. PAUL WHEATLEY-PRICE, MEDICAL ONCOLOGIST, OTTAWA

Dr. Quincy Chu says that staff had to step it up to ensure that proper care didn't wane during COVID but notwithstanding that effort, he recounts delays in seeing specialists, achieving diagnoses, and starting treatment. He says that patients with small-cell lung cancer set for chemotherapy would drop their appointments, scared to visit the hospital. Meanwhile, CT scan appointments would be moved, causing a lack of synergy with clinic appointments and all contributing to a chaotic rhythm.

Across provinces, the pandemic impacted resources in every health jurisdiction differently. For instance, in Ottawa, operating rooms were closed while in Nova Scotia they shut down only elective surgery. Dr. Stephanie Snow says it will take some time to untangle the full extent of what happened at a system level in various communities.

She does offer one example of a service that was stalled during COVID and is still not back to form. What's called EBUS (or endobronchial ultrasound) is an integral part of staging for many patients, particularly curative-intent patients where time is of the essence. EBUS is performed in the endoscopy unit, which is shared by gastroenterology – and which must undergo considerable safety and cleaning procedures.

“The wait list was bad before COVID, and then it got much longer,” Dr. Snow says. “That's a real bottleneck for us, and in fact we were forced to pivot and take patients to the operating room to perform a more old-fashioned procedure called mediastinoscopy so surgeons could access the lymph nodes.”

GREATER DIFFICULTY IN PROVIDING NUANCED, SPECIALIZED CARE

The management of lung cancer is a multilayered effort filled with nuances and specialized cases involving elements like language barriers, mobility challenges, and heightened stigma.

To nurse practitioner Bonnie Leung at BC Cancer, the resulting impact on these lower-profile elements was a key takeaway from COVID.

“The pandemic uncovered a lot of gaps and issues with the current health care system,” she says. “We witnessed many barriers that came up for patients in accessing care and being assessed in a timely fashion.”

These included but are not limited to:

BARRIERS WHEN ACCESSING CARE AND ASSESSMENT:

Patients not being able to have their support people join them in navigating the system.

Vancouver is a diverse, multicultural centre, and Bonnie says that new immigrants and those who don't speak or understand English well were at a major disadvantage due to COVID regulations. She says the team tried to mitigate this by getting family members on speakerphone, but that not having their usual advocates there in person was detrimental.

The sudden loss of volunteer drivers on whom many patients, notably older adults who can't drive and can't get around easily, previously relied to attend clinic.

“We heard that they didn't have the funds to take taxis to appointments, and patients struggled to find someone to help them get to in-person visits,” Bonnie says.

The reduced capacity of social workers and counsellors who attend to the psychosocial needs of lung cancer patients.

Referrals for social workers significantly increased due to the detrimental effect of isolation on the mental health of patients. There were long waits for patients to be assessed and support groups were canceled or diminished – a problem of infrastructure that caused their loneliness, depression and anxiety to deepen.

Care workers in the field whose community services and home assessments are important factors in how lung cancer patients are supported.

“This became more fractured, with some patients too fearful to even let these workers into their homes,” Bonnie says.

Rising discrimination among some populations of lung cancer patients – particularly those of Asian descent.

Bonnie knows one family where a son bought his mother pepper spray for protection when grocery shopping, due to rising COVID-fuelled antagonism against Asian Canadians. “The fear is very acute for our Asian patients, and it causes so much additional anxiety as they are told to stay home and isolate,” Bonnie says.

LOSS OF CONNECTION AMONG CARE TEAMS

The ability to provide effective lung cancer care, as well as avoid professional burnout, relies significantly on the team that helps each patient. This suite of teammates, from oncologists to nurses to dieticians to home care providers to families and patients themselves, grew fractured by the pandemic.

Dr. Paul Wheatley-Price says that roles and scope changed, nurses were reallocated to other units, and it led in some cases to disconnected teams, stressed health-care professionals, strained relationships, lack of clarity around who was to perform what work and, ultimately, professional isolation. For patients, it's meant dwindling interdisciplinary support.

"It was difficult as we did not necessarily have enough nurses who could deliver chemotherapy, attend to patients in palliative care, or assist with home visits," Dr. Wheatley-Price says. "They all got scooped up by COVID. We had some nurses who had to pay for chemo training themselves while they tried to support these patients amidst such stressful times."

In Hamilton, Ontario, Dr. Rosalyn Juergens witnessed how these shifting roles and reduced support in the COVID scramble impacted patient care. She was shocked to see one patient of hers, someone she knows who has considerable emotional stress, arrive in a wheelchair – a major drop in her health status. The fact that she went from being able to camp and hike on a regular basis to only being able to catch her breath at rest didn't get noticed by nursing during telephone calls, because emotional distress needs distracted from the new physical symptoms.

"Nobody in nursing recognized that a wheelchair was a major change in her performance status, because continuity of nursing staff was impacted by COVID," Dr. Juergens says, adding that when a physician and nursing team have an existing relationship with someone, identifying new key issues is easier and faster.

She says that nurses were redeployed from oncology centres, often seconded to ICUs, and decisions were made to compensate for reduced

staffing, such as providing nursing care only to patients with the highest symptom scores. Consistency of nursing care took a hit.

"Sometimes there were no nurses available to help and I often was in the position of being the only source of continuity of care for our patients," Dr. Juergens says. "Things are lost when patients don't have robust support around them. I hope we return soon to a world where we surround patients in the care they deserve."

Dr. Quincy Chu in Edmonton says that changing cohorts of nurses had a significant impact, as people who haven't seen a patient before simply can't deliver as personalized and sensitive care as needed. "My veteran nurse returned after a few months, and operations were immediately so much more fluid," he says.

Out east, Dr. Stephanie Snow relies on her close team of nurses that works flexibly together, helping with the many ins and outs of patient care. "They know certain tasks can wait until the next day, or the next week, and these experienced oncology nurses know how to organize care appropriately," she says. "They also keep our residents on track, as we are a teaching hospital where they play important roles, like filling chemo orders. I'd be lost without their incredible support, and the close bonds we share."

In all, COVID has threatened the close-knit care that is essential for lung cancer patients. Dr. Wheatley-Price says that these relational elements, including connections with patients and families, were far more difficult to maintain during the pandemic.

"IT WAS DIFFICULT AS WE DID NOT NECESSARILY HAVE ENOUGH NURSES WHO COULD DELIVER CHEMOTHERAPY, ATTEND TO PATIENTS IN PALLIATIVE CARE, OR ASSIST WITH HOME VISITS,"

DR. PAUL WHEATLEY-PRICE, MEDICAL ONCOLOGIST, OTTAWA

DELAYS IN MEDICAL RESEARCH BEAR CONSEQUENCES

Across Canada, one unique casualty of the COVID-19 pandemic was the ability to conduct clinical trials for other diseases – such as lung cancer. As funds and attention are directed toward COVID-19 at hospitals and academic centres, lung cancer projects were put to the side.

“Our clinical trials department was shut down and we are still reeling from that experience,” Dr. Juergens says. It’s been a slow recovery, and I know that across the country, this has really hurt a lot of middle-sized clinical trial departments.”

One such institution is the QEII Cancer Centre in Halifax, where Dr. Stephanie Snow says near-term repercussions is the loss of staffing inside their clinical trials unit. As a flurry of COVID trials opened, they tended to absorb the limited supply of trained research assistants and nurses. These were temporary assignments, but many staff didn’t return – and losing three research nurses from a group of five is a very impactful loss. As they replenish staff, Dr. Snow says it has handcuffed their ability to push forward with existing trials.

“I would have liked to have opened many trials but we have to focus on performing the ones we have already at the high-quality level they need to be,” Dr. Snow says. “We can’t overwhelm ourselves and then start to make trial deviations, so as a result I’ve had to turn down many interesting trials that would have been promising.”

Common to medical centres across the world, enrolments in clinical trials plummeted due to patients scared to visit hospitals and to research staff forced to take furlough or redirected to help strapped hospitals fight the pandemic.

In Montreal, Dr. Normand Blais says their clinical trials efforts fell far behind. “While it’s understandable to favor COVID projects to a certain extent, I am worried about our lost opportunities to launch new trials,” he says. “The pandemic forced long-lasting delays on trials that were nearly set to begin – and we are unable to open new trials without those ones first beginning.”

Across Canada, clinical cancer trial centres had a reduced capability to accrue and recruit new patients. Dr. Juergens says even when she is able to screen new patients to join a study, it is now more challenging to find the right candidates because patients are presenting sicker due to later diagnoses.

Dr. Snow says that other logistical challenges came up as well in trying to manage existing trials. Having to switch patients to virtual visits brings with it an entirely new concept for studying patients who are taking oral therapies. While they watched some patients drop out of trials, and others decline to participate when they would have without a pandemic, they also had to recalibrate how to virtually conduct trials while continuing to collect a high volume of data.

Patients lose access to emerging medications

One consequence of slowed lung cancer trials, as well as those that never got off the ground, is the delay in potentially game-changing new therapies and early discoveries.

Yet the more tangible impact is quite clear. It is widely known that, in joining a clinical trial, patients can receive new lung cancer treatments before they are widely available. COVID meant that they lost access to these medications, some of which could very well be classified as life-saving, as emerging breakthrough treatments hold great potential to influence outcomes for the better.

In Canada, Dr. Snow says that patients can sidestep an often lengthy drug approval process and access phase three or four trials where drugs are being offered, some that may already be approved by Health Canada but not yet by the province. For example, in Halifax they plan to launch a phase four trial where they aim to provide access to durvalumab for sick small cell lung cancer patients. Another of their trials is comparing two oral cancer drugs she says that are funded in different ways across Canada.

“Many of my patients don't qualify for PharmaCare despite having targetable and driver mutation-led cancers that need oral therapies,” Dr. Snow says. “Almost nobody can afford these drugs without private insurance, so we often use trials as a way for our patients to receive them.”

Using clinical trials, lung cancer teams across the country strategically choose trials that open a new avenue for their patients to be treated with the best new emerging medications. This avenue was closed by the pandemic.

“I find it very sad that what got lost in the COVID shutdowns were oncology clinical trials that are integral parts of cancer care delivery,” says Dr. Juergens. “We just wouldn't be where we are today with lung cancer if it weren't for clinical trials and research. I look forward to a day when we get back to a normal rhythm.”

“WHILE IT’S UNDERSTANDABLE TO FAVOR COVID PROJECTS TO A CERTAIN EXTENT, I AM WORRIED ABOUT OUR LOST OPPORTUNITIES TO LAUNCH NEW TRIALS... THE PANDEMIC FORCED LONG-LASTING DELAYS ON TRIALS THAT WERE NEARLY SET TO BEGIN - AND WE ARE UNABLE TO OPEN NEW TRIALS WITHOUT THOSE ONES FIRST BEGINNING.”

DR. NORMAND BLAIS,
MEDICAL ONCOLOGIST, MONTREAL



PART 4

ACCESS TO TREATMENT

Table 1 — Status of CADTH Drug Reimbursements (Within the Last 6 Years)

DRUG Generic name (Brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	CADTH Status	Phase Data Used
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®) 1st line	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	Final Recommendation January 30, 2020: Not recommended	3
atezolizumab (Tecentriq®) 2nd line	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
atezolizumab & bevacizumab (Tecentriq & Avastin)	For the treatment of metastatic EGFR and/or ALK positive non-squamous non-small cell lung cancer in patients who have progressed on treatment with targeted therapies.	December 6, 2018	May 24, 2019	Final Recommendation: July 3, 2020 Not recommended.	3
bevacizumab (Mvasi)	For treatment of patients with unresectable advanced, metastatic or recurrent non-squamous non-small cell lung cancer, in combination with carboplatin/paclitaxel chemotherapy regimen.	September 14, 2017	April 30, 2018	Final Recommendation: Final Biosimilar Dossier Issued January 14, 2019	3
bevacizumab (Zirabev)	For the treatment of patients with unresectable advanced, metastatic or recurrent non-squamous non-small cell lung cancer, in combination with carboplatin/paclitaxel chemotherapy regimen.	June 27, 2019	June 14, 2019	Final Recommendation March 28, 2019: File closed	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
brigatinib (Alunbrig®)	For the treatment of adult patients with anaplastic lymphoma kinase (ALK)-positive locally advanced (not amenable to curative therapy) or metastatic non-small cell lung cancer (NSCLC) previously untreated with an ALK inhibitor.	May 22, 2020	March 3, 2021	Final Recommendation April 21st, 2021: Recommended pending cost-effectiveness	3

Continued... Table 1 — Status of CADTH Drug Reimbursements (Within the Last 6 Years)

DRUG Generic name (Brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	CADTH Status	Phase Data Used
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 1st line	As monotherapy for use in patients with anaplastic lymphoma kinase (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 and feasibility of adoption (budget impact)	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 16, 2017 (previously treated with chemotherapy)	Final Recommendation November 2, 2017: Not Recommended (previously treated with chemotherapy)	2
dabrafenib (Tafinlar®) & trametinib (Mekinist®)	For the treatment of patients with metastatic non-small cell lung cancer (NSCLC) with a BRAF V600 mutation and who have not received any prior anti-cancer therapy for metastatic disease.	June 22, 2017	May 18, 2018	Final Recommendation March 18, 2021: Recommended pending cost-effectiveness and feasibility of adoption (budget impact)	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: Recommendation pending cost-effectiveness	3

Continued... Table 1 — Status of CADTH Drug Reimbursements (Within the Last 6 Years)

DRUG Generic name (Brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	CADTH Status	Phase Data Used
durvalumab (IMFINZI®) Stage III unresectable NSCLC	First-line treatment of adult patients with extensive-stage small cell lung cancer (ES-SCLC) in combination with etoposide and either carboplatin or cisplatin.	March 30, 2020	September 21, 2020	Final Recommendation July 27, 2021: Recommended for reimbursement	3
entrectinib (Rozlytrek®)	For the first-line treatment of adult patients with ROS1-positive locally advanced or metastatic non-small cell lung cancer.	August 15, 2019	May 5, 2020	Final Recommendation January 27th, 2021: Recommended pending cost-effectiveness	1 + 2
larotrectinib (Vitrakvi®)	For the treatment of adult and pediatric patients with solid tumours that have a Neurotrophic Tyrosine Receptor Kinase (NTRK) gene fusion without a known acquired resistance mutation, are metastatic or where surgical resection is likely to result in severe morbidity, and have no satisfactory treatment options.	November 26, 2018	July 10, 2019	Final Recommendation September 13, 2021: Recommended pending cost-effectiveness	1 + 2
lorlatinib (Lorbrena®) 1st line	For the first-line treatment of adult patients with anaplastic lymphoma kinase (ALK)-positive locally advanced (not amenable to curative therapy) or metastatic non-small cell lung cancer (NSCLC).	March 3, 2021	June 7, 2021	Currently under review	3
lorlatinib (Lorbrena®) 2nd line	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, 2019	Final Recommendation January 30, 2020: Not recommended	2
lurbinectedin (Zepzelca®) 2nd line	Treatment of adult patients with Stage III or metastatic small cell lung cancer (SCLC) who have progressed on or after platinum-containing therapy.	June 15, 2020	TBD	Submission planned for post Health Canada approval	2
nivolumab (Opdivo®)	For the treatment of patients with advanced or metastatic NSCLC who progressed on or after chemotherapy.	March 4, 2015	February 26, 2016	Final Recommendation June 3, 2016	3
Nivolumab in combination with Ipilimumab (Opdivo in combination with Yervoy)	Nivolumab, in combination with ipilimumab and 2 cycles of platinum-based chemotherapy for the first-line treatment of patients with metastatic or recurrent NSCLC with no EGFR or ALK genomic tumor aberrations.	May 26, 2020	August 6, 2020	Final Recommendation March 4, 2021: Recommended pending cost-effectiveness	3

Continued... Table 1 — Status of CADTH Drug Reimbursements (Within the Last 6 Years)

DRUG Generic name (Brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	CADTH Status	Phase Data Used
osimertinib (Tagrisso®) 2nd line	Osimertinib is indicated as adjuvant therapy after tumour resection in patients with stage IB-IIIa1 non-small cell lung cancer (NSCLC) whose tumours have epidermal growth factor receptor (EGFR) exon 19 deletions or exon 21 (L858R) substitution mutations.	December 18, 2020	January 3, 2021	Currently under review	3
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®)	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.	August 20, 2018	March 13, 2019	Final Recommendation May 31, 2019: Recommended pending cost-effectiveness	3
pembrolizumab (Keytruda®) 1st line	For the treatment of patients with locally advanced or metastatic urothelial carcinoma, as monotherapy, in adults who are not eligible for cisplatin-containing chemotherapy and whose tumours express PD L1 [Combined Positive Score (CPS) ≥10] as determined by a validated test, or in patients who are not eligible for any platinum containing chemotherapy regardless of PD L1 status.	April 11, 2019	April 11, 2019	Final Recommendation October 3, 2019: Not Recommended	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: Recommended pending cost-effectiveness	2 + 3
Selpercatinib (Retevmo®)	Indicated as monotherapy for the treatment of metastatic RET fusion-positive non-small cell lung cancer (NSCLC) in adult patients.	May 8, 2020	June 15, 2021	Currently under review	1 + 2
Sotorasib (Lumakras®) 2nd line	For the treatment of adult patients with KRAS G12C-mutated locally advanced (not amenable to curative therapy) or metastatic NSCLC who have received at least one prior systemic therapy.	May 28, 2021	September 10, 2021	TBD	2
Tepotinib (Tepmetko®)	For treatment of adult patients with locally advanced unresectable or metastatic non-small cell lung cancer (NSCLC) harbouring mesenchymal-epithelial transition (MET) tyrosine kinase receptor exon 14 skipping alterations.	February 3, 2021	May 27, 2021	Currently under review	2

As of September 30, 2021 ALK = anaplastic lymphoma kinase CNS = central nervous system EGFR = epidermal growth factor receptor NSCLC = non-small cell lung cancer TKI = tyrosine kinase inhibitor

Table 2 – Date of Provincial Coverage

As of September 30, 2021

Drug Name	BC	AB	SK	MB	ON	QC	NS	NB	NL	PEI
alectinib (1st and 2nd line)	May 1, 2019	March 1, 2019	February 11, 2019	May 31, 2019	April 17, 2019	February 1, 2019	Oct 3, 2019	May 16, 2019	September 27, 2019	Not Funded
atezolizumuab (2nd line NSCLC)	November 1, 2019	October 7, 2019	February 11, 2019	February 13, 2019	December 6, 2019	February 1, 2019	Not Funded	October 30, 2019	Not Funded	Not Funded
Bevacizumab (Mvasi)	November 1, 2019	Not Funded	January 27, 2020	September 23, 2019	August 19, 2019	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
brigatinib (Alunbrig®) 1st line	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	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	October 3, 2019	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 (ROS1)	July 1, 2020	July 30, 2020	August 1, 2020	Not Funded	Not Funded	November 11, 2020	Not Funded	July 16, 2020	May 1, 2020	Not Funded
dabrafenib (Tafinlar®) & trametinib (Mekinist®)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
dacomitinib (Vizimpro®)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
durvalumab	February 1, 2020	April 10, 2020	January 1, 2020	December 16, 2019	January 22, 2020	Not Funded	February 1, 2020	March 20, 2020	June 1, 2020	Not Funded
entrectinib	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	August 18, 2021	Not Funded	Not Funded	Not Funded	Not Funded
larotrectinib (Vitrakvi®)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	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)	January 1, 2020	April 10, 2020	March 1, 2020	April 2, 2020	January 10, 2020	Not Funded	Not Funded	March 19, 2020	February 20, 2020	Not Funded
osimertinib (2nd line)	October 1, 2018	November 20, 2018	November 1, 2018	October 18, 2018	October 3, 2018	November 8, 2018	November 1, 2019	February 27, 2019	February 20, 2020	Not Funded
pembrolizumab (1st and 2nd line)	February 1, 2018	February 16, 2018	December 15, 2017	December 7, 2017	January 17, 2018	November 15, 2017	May 24, 2018	May 2, 2018	May 30, 2018	August 1, 2019
pembrolizumab w/ pemetrexed & platinum chemotherapy	June 1, 2020	September 15, 2020	May 1, 2020	May 1, 2020	April 24, 2020	April 8, 2020	May 1, 2020	July 16, 2020	June 1, 2020	Not Funded

Table 3 – Number of Days from Date of FDA Approval to Date of Provincial Coverage

As of September 30, 2021

DRUG Generic name	FDA APPROVAL DATE	BC	AB	SK	MB	ON	QC	NS	NB	NL	PEI
alectinib (1st line)	November 6, 2017	541	480	462	571	527	452	696	556	690	Not Funded
alectinib (2nd line)	December 11, 2015	1,237	1176	1,158	1,267	1223	1148	1,392	1,252	1,386	Not Funded
atezolizumab 2nd line	October 18, 2016	1,109	1,084	846	848	1,144	836	Not Funded	1,107	Not Funded	Not Funded
bevacizumab (Mvasi)	September 14, 2017	778	Not Funded	865	739	704	Not Funded				
brigatinib (Alunbrig®) 1st line	May 22, 2020	Not Funded									
ceritinib	April 29, 2014	1,586	1,645	1,569	1,542	1,626	Not Funded	1983	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 (ROS1)	March 11, 2016	1573	1602	1,604	Not Funded	Not Funded	1,706	Not Funded	1,588	1,512	Not Funded
dabrafenib (Tafinlar®) & trametinib (Mekinist®)	June 22, 2017	Not Funded									
dacomitinib (Vizimpro®)	September 27, 2018	Not Funded									
durvalumab	February 16, 2018	715	784	684	668	705	Not Funded	715	763	836	Not Funded
entrectinib	May 5, 2020	Not Funded	471	Not Funded	Not Funded	Not Funded	Not Funded				
larotrectinib (Vitrakvi®)	November 26, 2018	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	623	723	683	715	632	Not Funded	Not Funded	701	673	Not Funded
osimertinib (2nd line)	November 13, 2015	1,053	1,103	1,084	1,070	1,055	1,091	1449	1,202	1560	Not Funded
pembrolizumab (1st line)	October 24, 2016	465	480	409	417	450	387	577	555	583	1011
pembrolizumab (2nd line)	September 4, 2014	1,246	1,261	1,198	1,190	1,231	1,168	1,358	1,336	1,364	1,792
pembrolizumab w/ pemetrexed & platinum chemotherapy	August 20, 2018	651	757	620	620	613	597	620	696	651	Not Funded



CONCLUSION

LUNG CANCER CANADA BELIEVES

The following key learnings reflect the opinions of Lung Cancer Canada and its patient and professional stakeholder groups.

Canadians must not let fear of COVID prevent them from being checked out

In lung cancer, timely diagnosis and treatment is crucial – weeks matter, months matter. It is vital to get the specialized care needed if feeling unusually sick or experiencing any symptoms. Don't head to the ER a month later than you could have, because untreated lung cancer is far worse than the risk of getting COVID-19.

Lung cancer patients deserve standardized, equitable care

The pandemic has pulled back the curtain even further on the need for equitable care across the country. Two Canadians with the same diagnosis should not be facing different treatment paths.

WHILE CARE MUST BE STANDARDIZED, INDIVIDUAL NEEDS MUST BE PRIORITIZED

The management of lung cancer is a multilayered effort filled with nuances and specialized cases involving elements like language barriers, mobility challenges, demographic needs, cultural considerations, and individual choices – all of which must be considered in order to provide lung cancer patients with their best possible care.

BRING CLARITY AMONG CHAOS TO VULNERABLE CANADIANS

Lack of knowledge, shifting directives, and inconsistent messaging across the country have deeply impacted people with lung cancer. For example, for the critical vaccine rollout, some provinces had clear plans, while others stoked confusion over priority cohorts and definitions around “immunocompromised.”



A new focus on interdisciplinary care teams must be prioritized to surround patients with the support they need

Shifting roles and reduced support in the COVID scramble has impacted patient care. Without consistent procedures, processes and teams in place, patients can easily slip through the cracks when busy health care professionals can't remain laser focused on the patients who need them most. Accountability should not begin and end solely with oncologists.



Caregivers are important members of the health-care team and must be treated as such

There are devastating consequences that patients face when their core supports are removed. Caregivers barred from appointments or otherwise shut out from their loved ones' care due to the pandemic caused undue mental health strain on families and patients who were forced to navigate appointments alone, without a second set of ears or a shoulder for support. Caregivers must be considered essential not only to a patients' well being but also to their outcomes.



COVID-19 must not overshadow priority lung cancer care

We must prioritize high-quality testing, screening and diagnostic procedures for Canadians in every province and territory. We must enable broad access to sophisticated care regardless of where someone lives. We must equitably fund the most promising personalized medicines. We must not accept barriers to undiagnosed and diagnosed Canadians with lung cancer getting timely clinical support.

Patients must be empowered with choice and control wherever possible

Lung cancer is an individual journey, and part of personalized care is ensuring individual needs are front and centre. Pandemic or not, all decisions around the delivery of care should be made in consultation between patients and providers.

Conquering stigma is more important than ever

Society is more polarized than ever due to COVID, and polarization is a breeding ground for stigma – already a long rooted issue in lung cancer. Encouraging people to ask helpful questions such as “how are you feeling?” or “how can I help?” promotes kindness rather than judgement on a disease linked to smoking.

THE MENTAL HEALTH OF BOTH PATIENTS AND PRACTITIONERS CANNOT BE IGNORED

The oncology community is in a process of reconstruction, of cutting into the deep backlog of surgeries, and of setting systems of care back upright after existing in survival mode throughout the pandemic. But this is an exhausted group of professionals, and oncologists across Canada are worried about their staff’s wellness long into the wake of COVID. Moving forward, we must do more to help those who are running on empty.

IT IS TIME TO TAKE SERIOUS ACTION ON PHYSICIAN BURNOUT

COVID blew the doors open on this already widespread issue. It is now time for a full and open discussion, and time to take meaningful steps to address physician distress and wellbeing. Medicine must become a more healthy system that tends not only to sick patients, but also helps to heal the healers. By doing so, we will create greater, more interpersonal relationships between those forced to navigate the health-care system, and those providing the care that they find.



Cancer research and funding must be prioritized despite the demands of COVID-19

COVID has demanded the attention of health-care research and budgets. Yet we're at very real risk of losing the progress we've made bringing new therapies to market, promoting coverage of oral therapies, and extending screening. Deficits in funding and research are already creating consequences that will be felt for years to come. Governments must revert from money-saving models of care. It is not sustainable for health-care professionals to overcome systemic gaps alone.



Let's use COVID as a catalyst to strengthen and unify the lung cancer community from coast to coast to coast

It is so important for patients to feel a sense of bond with a community of people who understand. It's time to deepen our connections and break down provincial borders by leveraging new video conferencing tools, bolstering resources, holding more supportive events virtually, and using social media groups to reach those who many want those connections but aren't able to access peer support through other means.



The pandemic highlighted the importance of end-of-life care

Many Canadians with lung cancer died during COVID-19, tragically without the right supports in place. COVID-19 has led to a potentially deeper respect for the importance of palliative care, which can be delivered in many settings, from hospitals to long-term care facilities to nursing homes, to living rooms. Lung cancer is the most fatal of all malignancies, and how we manage end-of-life care must be a careful discussion between all parties, no matter the circumstances. Excellent palliative care must be delivered anywhere and ensure that loved ones are not separated in the final days.



Patients and their families must be their own advocates in their care journeys

Our health-care systems are not without fault. They must listen and trust their bodies, and pursue any concerns without hesitation. For virtual care, push to develop personal ties with care providers. Stronger connections bring greater support and a more successful journey. Nothing tested the ability to be a self-advocate more than the pandemic.

FINAL WORDS

This 2021 Faces of Lung Cancer Report is dominated by the issue that has unfortunately dominated all conversations these past two years. We recognize that in exploring the challenges wrought by COVID-19, the portrait is a gloomy one as we reflect on how the pandemic impacted patients with lung cancer.

Nevertheless, let's finish on an upbeat note of hope and achievement as we also look forward to breaking through the pandemic and inching toward a semblance of normality. To that end, let us not lose sight of some hopeful trends:

- Survival rates for this disease, while still not very good, are indeed climbing – to the highest they have ever been in Canada. This progress is significant, and the future looks considerably brighter still.
- In the past, survival rates have been poor as most patients are diagnosed in late stages. Earlier diagnoses are clearly the answer and, for years now at Lung Cancer Canada, we have lobbied federal and provincial governments to fund lung cancer screening programs that use low-dose CT scans to catch lung cancer at stage 1. The first major recent development occurred in late 2020 when British Columbia announced a lung cancer screening program. In early 2021 Ontario followed suit and, in June, Quebec announced a lung cancer screening demonstration project. Together these initiatives – and the ones to come – will save lives, and we continue to advocate for all provinces and territories to open such programs.

Science works. As more molecular subtypes of lung cancer are discovered we also have in place matching targeted treatments for each. In 2021, Canada made significant progress here in two key ways:

- We have improved testing with more access to next generation sequencing, where lung cancer biopsies are analyzed in one test for ALL potential genetic targets. This is a critical area and in 2021 we made major strides with more funding for NGS testing to become available and accessible to more and more patients.
- Health Canada and Health Technology Assessment programs are approving more treatments for rare subtypes of lung cancer are being approved. While time is still needed to approve public funding for some of these options, we are definitely moving in the right direction.

WE DARE TO HOPE!

As we look to what's in store for 2022, let us be cautiously optimistic. We have seen so much progress in lung cancer, from screening, new drug treatments like immunotherapy and targeted therapies, smoking cessation programs, stigma erosion, novel surgical and radiotherapy approaches, and greater awareness and advocacy.

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