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# THROWN UNDER THE BUS!

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DISRUPTION OF CANCER CARE IN CANADA  
DURING THE COVID-19 PANDEMIC

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Canadian Cancer Survivor  
Network (CCSN)

Research commissioned by CCSN for three surveys conducted by Leger

## Executive summary

*"I feared going to the hospital for my CT scan. I feared getting COVID. I feared NOT getting my CT scan, as then I would have to wait LONGER for any results,"* wrote a stage 2 colorectal cancer patient in Ontario, who sums up feelings shared by many cancer patients and caregivers affected by the disruptions to cancer care during the pandemic: *"Not knowing is worse than knowing. Knowing gets action put into place. Fear breeds anxiety, and that is NOT GOOD for cancer patients. I feared being bumped out of the system. I FEEL DISPLACED. I now feel lost. I feel that NO ONE cares about me/my health. I have had SO many appointments cancelled, delayed, changed, pushed out, I can no longer count them. ... We were THROWN UNDER THE BUS. PERIOD."*

The impact of the COVID-19 pandemic on Canadian cancer patients has been severe. To assess this impact, the Canadian Cancer Survivor Network (CCSN) commissioned Leger to conduct three surveys of Canadian cancer patients, caregivers, and people awaiting a possible cancer diagnosis. The surveys were conducted in May–June 2020, December 2020, and June–July 2021, respectively. The results show that the pressure from the pandemic on Canada's healthcare system has led to another public health crisis.

- **Cancer patients have not been able to get the cancer care they need when they need it.** Over four in ten patients, seven in ten caregivers, and nearly six in ten pre-diagnosis patients have had appointments cancelled or rescheduled during the pandemic.<sup>1</sup> Three in ten caregivers, 18 per cent of pre-diagnosis patients, and seven per cent of patients have had a surgery or other procedure cancelled. Of those who have had procedures cancelled, more than one in four patients, nearly one in three caregivers, and more than one in two pre-diagnosis patients were still waiting for their procedure to be rescheduled. On average, patients waited 55 days until they had a new date for their procedure, while caregivers waited an average of 36 days.
- **Stress and anxiety** about cancer care are overwhelmingly common. A caregiver for a Manitoba breast cancer patient writes: *"The anxiousness never goes away, it's one thing after another, one let down after another."* More than half of all respondents (58 per cent) were concerned about being able to receive cancer treatment in a timely fashion.
- **Getting COVID-19** is the most common fear named by patients and caregivers. It affects their mental health and makes it stressful to go out, including to seek medical care.
- Some cancer patients are **afraid to get in-person medical care** for cancer-related symptoms because they feel their COVID-19 risk is too great. One in three

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<sup>1</sup> Statistics are from CCSN's third and most recent survey, conducted in June and July 2021, except where otherwise noted.

caregivers and pre-diagnosis patients chose not to go to the ER for cancer-related symptoms during the pandemic.

- **Caregivers** have been adversely affected more than others, both by disruptions to cancer care and by stress and anxiety. Over one in three caregivers said the person they care for has had a surgery or other procedure postponed, and 77 per cent of caregivers said they were concerned about the patient they are caring for getting timely cancer treatment.
- Patients' and caregivers' **well-being** has been adversely affected in every dimension – mental and physical. Over half of all respondents, including four in five caregivers, said the pandemic has affected their levels of anxiety.
- The pandemic has caused **financial difficulties** for people affected by cancer. Most commonly, they have had fewer hours of work, difficulty meeting dietary needs, or job loss. Half of all caregivers and one in four patients said that their financial situation has been adversely affected.
- Rates of **vaccination against COVID-19** among cancer patients and their caregivers are very high. As of July 2021, these rates were significantly higher than the vaccination rate of Canadians as a whole. Nearly nine in ten cancer patients and their caregivers have been at least partially vaccinated.

In short, COVID-19 has had disastrous secondary effects for cancer patients, caregivers, and pre-diagnosis patients: their access to essential cancer care, safety from COVID-19, and mental and physical health have all been put in jeopardy. CCSN calls on governments to take the experience of people facing cancer and their caregivers into account and to include provisions for the continuation of essential cancer care in planning for future pandemics and crises. Our public institutions must be equipped so that the next public health crisis does not leave cancer patients behind.

## Background

### About the surveys

To discover how the COVID-19 pandemic and the public health response to it affected cancer patients, the Canadian Cancer Survivor Network (CCSN) commissioned Leger to conduct three surveys of Canadian cancer patients, cancer caregivers, and people awaiting a possible cancer diagnosis.

The three surveys took place about six months apart: the first was conducted from May 22 to June 10, 2020, the second from December 3 to 29, 2020, and the third from June 10 to July 4, 2021, roughly aligning with the first three waves of the pandemic.

Broadly speaking, the surveys sought to answer these questions:

- What changes and disruptions to cancer care did respondents experience because of the public health response to COVID-19?
- What has been the mental and emotional impact on respondents of these disruptions to cancer care?
- Are respondents afraid to seek medical care because of COVID-19?
- How has the pandemic affected respondents' well-being?

### About CCSN

The mission of the Canadian Cancer Survivor Network (CCSN) is to educate those affected by cancer, including patients, survivors, and caregivers, about issues associated with managing their cancer, and to connect them with supports; to educate the public about the challenges facing those affected by cancer; and to advocate on behalf of cancer patients for public policy that eases hardships, improves care, and extends the lives of cancer patients and survivors.

CCSN undertook these surveys in accordance with CCSN's mandate to conduct research on the barriers that confront those affected by cancer in Canada, raise awareness about these barriers, and call for change where it is needed. The surveys have formed the basis of CCSN's [Cancer Can't Wait!](#) project about the impact of reduced access to cancer care

during the pandemic, which includes webinars, articles, and pan-Canadian action campaigns.

## Respondents

### Recruitment

Nearly all survey respondents were drawn from Leger's LEO research panel. (Only the first survey had some respondents from another source: 51 respondents signed up from a link on CCSN's website.) The surveys used *non-probability sampling*, which means that the respondents came from a pre-existing group of people (in this case, the LEO panel). The alternative, *probability sampling*, would mean selecting respondents randomly out of the entire population of interest – in this case, Canadian adults who are cancer patients, caregivers, or in the process of being diagnosed. Non-probability sampling is typical for healthcare research in Canada.

### Categories

Respondents were grouped into three categories: patients, caregivers, and pre-diagnosis patients. For the most part, this report presents results from the surveys broken down according to these categories.

**Patients:** people who have been diagnosed with cancer. They may or may not be in active treatment.

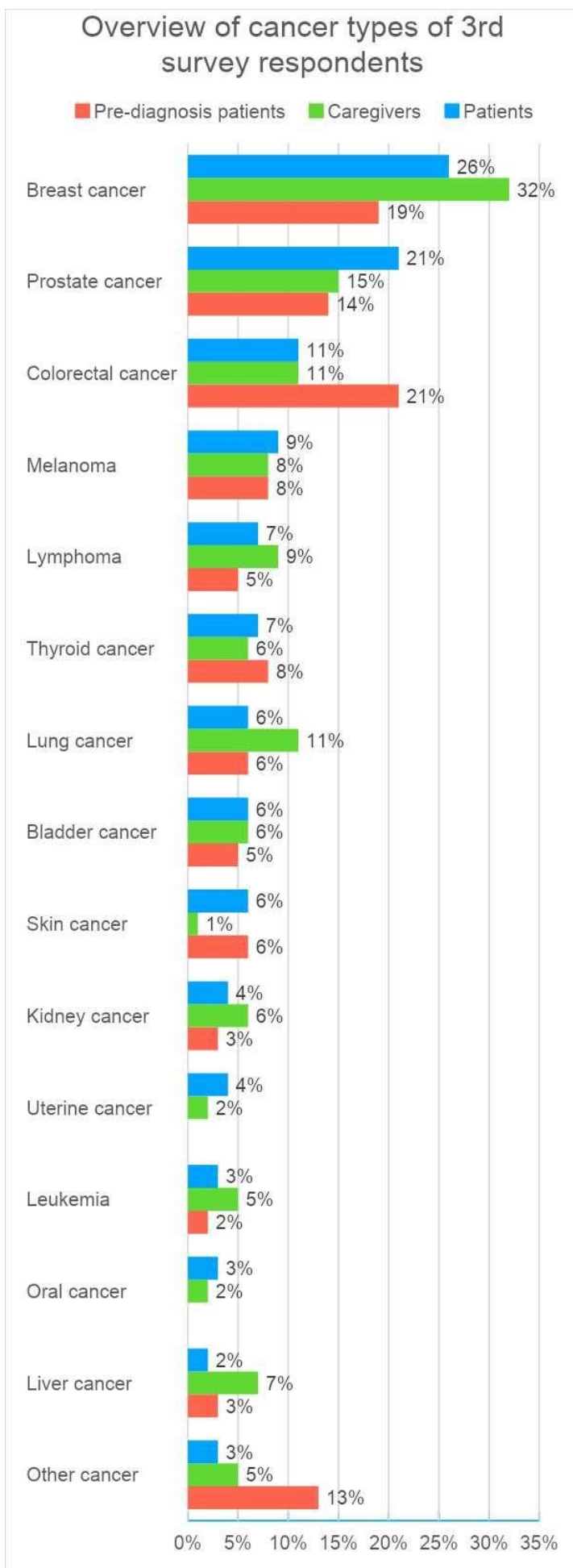
**Caregivers:** people who take care of someone, such as a family member or friend who has cancer, responding on behalf of the person they care for.

**Pre-diagnosis** patients: people who are in the process of determining whether they have cancer. They may be waiting for their diagnostic test appointment or waiting for test results.

	First survey	Second survey	Third survey
<i>Patients</i>	960	1198	1159

<i>Caregivers</i>	206	248	233
<i>Pre-diagnosis</i>	77	192	110
<b>Total</b>	<b>1243</b>	<b>1638</b>	<b>1502</b>

For brevity, this report often uses the term “cancer patients” to refer to the entire set of respondents to all surveys, without distinguishing between categories. When presenting specific results, however, the categories are distinguished; in this case “patients” refers only to people who have had cancer themselves.



## Demographics

The group of respondents for each survey was intended to be representative of the Canadian population as far as possible (with respect to gender, age, province of residence, etc.). In this section, the information is for all three surveys, except where otherwise noted. All respondents were adults (18 years or over). No more than 35 per cent of respondents were in remission in each survey (excluding pre-diagnosis patients).

### *Patients*

Patients were fairly evenly split by gender – the difference was greatest in the third survey, in which 54 per cent of patients were women and 46 per cent were men. Patients tended to skew older – more than half were 65 years old or older, and more than half were retired.

Breast cancer, prostate cancer, and colorectal cancer (in that order) were the most common cancer types for patients; more than half had one of these three types of cancer. More

patients were in remission than at any other cancer stage, ranging from 35 per cent of patients in the first survey to 39 per cent in the third. More than half of patients were diagnosed with cancer within the last five years (from the time each survey was taken).

### *Caregivers*

Caregivers tended to skew female – between 60 and 64 per cent of caregivers were women. Between one in five and one in four caregivers were caring for their spouse or partner with cancer.

More than half of caregivers were caring for someone with breast cancer, lung cancer, or prostate cancer. Breast cancer was the most common type of cancer. Unlike with patients, lung cancer was also quite common, taking second place in the second survey and third place in the other two.

The cancer stages of those the caregivers were caring for tended to be more evenly distributed than with patients; the percentage of caregivers whose loved one was at each cancer stage varied between 10 and 25 per cent among the three surveys. As with patients, more than half of caregivers said their loved one was diagnosed with cancer within the past five years.

### *Pre-diagnosis patients*

Respondents in the pre-diagnosis stage were mostly men. In the first survey, two out of three were men; the third survey was more evenly split, with 55 per cent identifying as male.

Most pre-diagnosis patients knew what type of cancer they might have; this percentage declined from 68 per cent in the first survey to 57 per cent in the third. Colorectal cancer, breast cancer, and prostate cancer (in that order, except for the first survey) were the most common cancers for which pre-diagnosis patients were being tested. (Prostate cancer was the most common in the first survey, which makes sense given that two thirds of pre-diagnosis respondents in that survey were men.) A minority<sup>2</sup> of pre-diagnosis patients had already been diagnosed with cancer in the past.

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<sup>2</sup> The absolute numbers are so small in this case – between 6 and 19 respondents – that percentages are not meaningful.



## Disruption of cancer care

The interruptions to scheduled cancer care during the pandemic have been widespread and have caused great difficulties for patients. These disruptions include cancelled and postponed in-person appointments, suspension of elective surgeries<sup>3</sup> and other procedures, and screening programs closing.

*“During the first wave, my cancer clinic was almost 'shut down,' in effect,” wrote an ovarian and esophageal cancer patient in Quebec. “My regularly scheduled appointment was cancelled and not rescheduled. Instead of every six months, it was over a year before I was seen, and by then my cancer marker had tripled, when for 1.5 years it had been stable.”*

Although access to cancer care was most widely curtailed early in the pandemic, the consequences of that lack of access reverberate into the present. Deferred appointments, procedures, and screenings are liable to cause worse outcomes later on.

Caregivers, pre-diagnosis patients, and metastatic cancer patients – for whom cancer is often a greater source of stress than for other patients in the first place – have consistently been harder hit by disruptions to scheduled care.

### Appointments

Changes to appointments were, by a wide margin, the most common kind of disruption to scheduled cancer care during the COVID-19 pandemic. Eighteen months after the start of the pandemic, half of the cancer patients across Canada reported that a cancer care appointment had been cancelled, postponed, or rescheduled. Metastatic cancer patients were affected significantly more, with seven in ten having had a cancelled, postponed, or rescheduled appointment. Recently diagnosed patients are not far behind – six in ten say they experienced these kinds of disruptions.

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<sup>3</sup> “Elective surgeries” are not optional surgeries, as the word “elective” might suggest, but scheduled surgeries, as opposed to emergency surgeries.

### *Appointments changed from in-person to remote<sup>4</sup>*

By far, the most common kind of change in appointments was rescheduling an in-person appointment as a telephone appointment or another kind of remote appointment. This happened to four in ten current patients and pre-diagnosis patients and just over fifty per cent of caregivers.

These numbers did not show significant change between the three surveys, suggesting that the shift away from in-person appointments occurred mostly in the early stages of the pandemic. Pre-diagnosis patients are the exception: in June 2020, almost sixty per cent said they had had an in-person appointment changed so that it was no longer in-person, but in the second survey this dropped to forty per cent. This would make sense if, by December 2020, more people had entered the pre-diagnosis stage during the pandemic; fewer of them would have had in-person appointments to begin with.

Cancer patients' reactions to the move from in-person to remote appointments varied: some were glad to be able to see their doctor during a lockdown without having to leave their home, while others felt they were not able to communicate as effectively over a phone or video call. For more information on how respondents communicated with healthcare professionals, see the section "Ways of communicating."

### *Cancelled or postponed appointments*

Delayed appointments were dismayingly common: one in four patients, one in three pre-diagnosis patients, and two in five caregivers reported that their doctor had cancelled or postponed an in-person appointment related to their cancer during the pandemic.

Respondents cite these delays as a continual source of stress. They find that *"the whole process brings fears and concerns,"* as a stage 3 breast cancer patient in Quebec wrote: *"waiting for someone to contact us to schedule the appointments, waiting for the results, waiting to see the doctor – all this is even more intense with this pandemic. We are always afraid of cancellation, postponement, and contracting COVID-19."*

Postponing appointments by any length of time has serious consequences for cancer – a fact of which respondents are aware. *"At first I was confused and thought it was a*

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<sup>4</sup> "Remote appointments," in this report, means appointments that didn't take place in person. Most remote appointments took place by telephone, but there were some video appointments as well.

*hospital scheduling error - when I realized it was due to covid I was very anxious,” said an ovarian cancer patient in remission from Ontario, referring to a cancelled appointment. “I depend on my checkups to make sure my bloodwork is stable and if the cancer returns, we catch it in time to be proactive. The anxiety of living with cancer is unexplainable to someone who has not experienced it.”*

A delayed appointment may mean a missed opportunity to detect a change in the patient's cancer – for example, if the cancer metastasizes, or a cancer that was in remission returns. The longer such a change goes undetected, the greater the likelihood of worse outcomes later on.

The most significant changes to postponed appointments happened between the first and second waves of the pandemic: fewer current patients and pre-diagnosis patients in the second survey said they had experienced cancelled or postponed appointments – a change of about five percentage points. For caregivers, on the other hand, prevalence of postponements and cancellations stayed virtually the same.

This suggests that the disruptive changes to in-person appointments occurred in the first wave of the pandemic. There may be more current and pre-diagnosis patients than caregivers who only began their cancer care during the pandemic and so missed the upheaval of the first wave.

### *Wait times to get new appointments*

The length of time that cancer patients have had to wait to get a new appointment date varies a great deal – from within a week of the original appointment date to several months later. Moreover, many were still waiting for a rescheduled appointment: as of summer 2021, one in three patients (34 per cent), one in five caregivers (20 per cent), and one in three (28 per cent) pre-diagnosis patients were still waiting.

For those who did have rescheduled appointments, wait times tended to hover around one month. However, there were some differences between patients, caregivers, and pre-diagnosis patients. On average, patients had to wait 30 days to get a new appointment date; caregivers waited an average of 20 days. Both of these averages show improvement compared to the second survey in December 2020: at that time, patients reported an average wait time of 38 days, and caregivers 27 days. For pre-diagnosis patients, on the other hand, the average wait time from the third survey – 28 days – is virtually unchanged from the 27-day average wait from the second survey.

Although a wait of one month before knowing when you will see the doctor is stressful enough, it should be noted that the above figures are averages: many have had to wait up to several months. The prolonged uncertainty has taken a toll on patients' and caregivers' mental health. *"It is very concerning as I do not know if and when the specialist will begin to see patients,"* wrote a stage 1 colorectal cancer patient in Ontario. *"This scares me."*

## Tests

Delayed tests have cancer patients feeling left in the dark about their disease. Sasha, an Alberta lymphoma patient whose cancer is in remission, suspected that her cancer has recurred, but didn't know for sure because her CAT scan was postponed. Her greatest concern, she wrote, is *"that they will not be able to detect re-occurrence fast enough and it will have spread before I get to treatment."* For her and others in the same position, regular testing is the only way they can discover if they are still in remission.

Fifteen per cent of patients and caregivers surveyed in July 2021 have had a lab or diagnostic test cancelled or rescheduled since the pandemic began. For caregivers, this has been much more common than for patients – about one in three caregivers (34 per cent) say the person they care for has had a test delayed, compared to just over one in ten patients (11 per cent).

Although delays in testing haven't seen significant change over the three surveys, the numbers are consistent with a slight downward trend in disruptions to scheduled care. In December 2020, eighteen per cent of survey respondents had experienced cancelled or rescheduled tests. This difference is likely due to caregivers often being the navigators for their loved ones, and therefore responsible for keeping track of appointments.

Caregivers are acutely aware of the potential consequences of finding changes in their loved one's cancer too late. *"My concerns are that the tests previously booked were rescheduled due to COVID-19,"* writes one caregiver for a colorectal cancer patient in Alberta. *"This greatly concerns me, as when you are dealing with cancer, the sooner a problem is detected and can be acted upon, the chance for a positive/successful outcome is increased. Being successful with cancer depends upon timely action."*

## Screening

Disruptions to cancer screening during the pandemic have been quite common: over one in three caregivers (36 per cent) and over one in four pre-diagnosis patients (26 per cent) report that they have had a routine screening cancelled or rescheduled since the beginning of the pandemic. Patients had fewer routine screenings cancelled or postponed, at 18 per cent. This constitutes a significant improvement from the first survey in July 2020, in which 23 per cent of patients experienced cancelled or postponed screenings.

*“Three weeks ago my [oncologist] found a cyst in my other breast and I’m told it’s a three month wait for a diagnostic screening mammogram even though I’ve had cancer,”* wrote a stage 1 breast cancer patient in British Columbia. *“Totally unacceptable.”* Screening is no less important for people who have had cancer than for those who haven’t: someone who has had one tumour may be more likely to have another, and screening is key to detecting whether that has happened.

The widespread decline in screening across Canada in the early stages of the pandemic will result in cancers being diagnosed at later stages. The Quebec Ministry of Health reports over 60,000 fewer colonoscopies were completed between April 2020 and January 1, 2021, versus the same period from the previous year. Alberta and Nova Scotia also saw reductions in cancer diagnoses and surgeries during the pandemic. And the Ontario Breast Screening Program (OBSP) performed 149 mammograms for routine cancer screening in April 2020, compared with 61,655 during the same month one year prior.

Even as provincial health authorities begin resuming cancer screening programs, the backlog of tests means that the delays are not over. Some patients fear that if they develop new symptoms or problems, their concerns might get lost between COVID-19 chaos and the backlog of appointments.

*“My fear is that I’d get a relapse and it wouldn’t be a priority for doctors,”* wrote an Ontario stage 3 carcinoma patient. *“Living with cancer, even being in remission is a constant stress.”*

## Procedures

The cancellation of elective surgeries<sup>5</sup> across Canada in the early stages of the pandemic had a massive impact on cancer patients. *“It’s quite devastating to me,”* wrote a cervical cancer patient in Ontario about her postponed surgery, *“as this surgery would have relieved many of my worst symptoms.”* For that patient as well as for many others, the impact has been both physical and mental: their pain and debilitating symptoms have been prolonged, and they are burdened with stress, anxiety, and despondency.

As of July 2021, 12 per cent of all respondents, or just under one in eight, have had a scheduled procedure – for example, a surgery – cancelled or postponed during the pandemic. In the first survey, about a year previous, 15 per cent of respondents said they had had a procedure delayed: the change is not significant on its own, but it is consistent with other survey results that show slight improvements over time.

Although it is good that the number of delayed surgeries appears to be decreasing, the backlog of surgeries from earlier in the pandemic remains. Because of this, there are still patients who do not know when their surgery will be rescheduled.

*“Having my endoscopy procedure postponed has increased my worries,”* said a stage 2 stomach cancer patient in Quebec. *“Now I have to wait, and I have no idea when it will be rescheduled. I want to know that my cancer treatment was successful and that the cancer has not returned. This uncertainty is affecting my quality of sleep. I need to know if my cancer has come back.”* This pressing uncertainty and sense of a lack of control has caused continual stress for many patients and caregivers.

Surgeries cannot, after all, be postponed for arbitrarily long. Cancer doesn’t wait. A delay of months can allow symptoms to worsen or the cancer to spread further. When the surgery does take place, it may be more difficult than it should have been. *“Because of the delay in getting an appointment with my surgeon and then another delay for surgery, my cancer quadrupled in size causing a simple surgery [to be] more complicated,”* wrote a lymphoma and melanoma patient in Ontario who has experienced these consequences firsthand.

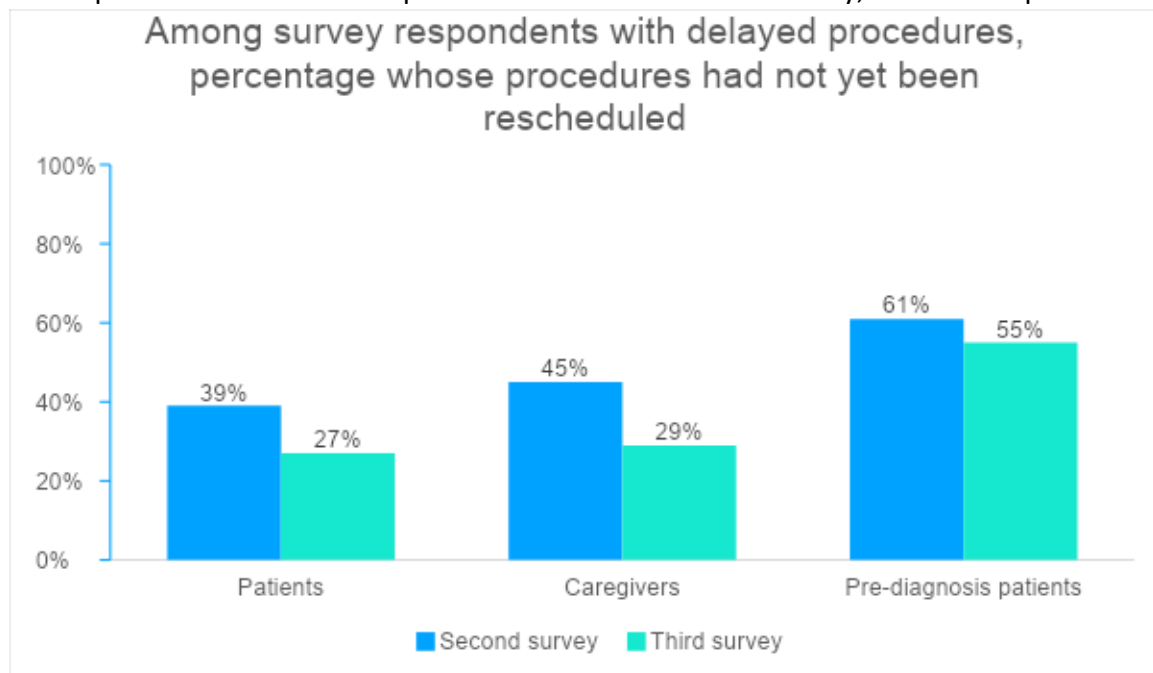
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<sup>5</sup> ‘Elective’ might sound like it means ‘by choice,’ but in the context of surgery, this term refers to surgeries that are scheduled in advance, as opposed to emergency surgeries. Surgeries for cancer care are therefore largely elective.

### *Wait times for rescheduled procedures*

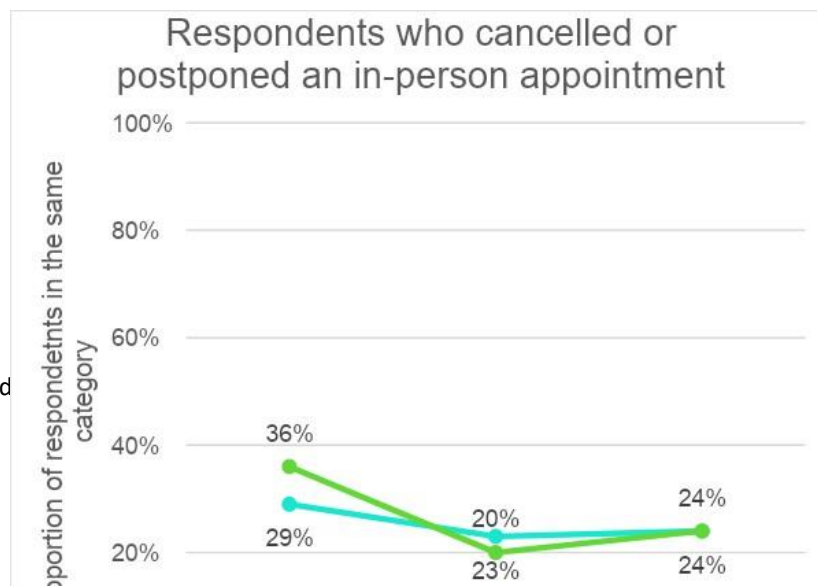
Many respondents who had a procedure postponed still did not know when it would take place. More than one in four patients (27 per cent), just under one in three caregivers (29 per cent), and half of pre-diagnosis patients<sup>6</sup> who responded to CCSN's third survey were still waiting for their procedure to be rescheduled. Wait times for those who have received a new date for their cancelled procedure have been alarmingly long: on average, patients waited 55 days until they had a new date, while caregivers waited an average of 36 days.

This represents a moderate improvement from the second survey, in which 39 per cent



of patients, 45 per cent of caregivers, and 61 per cent of pre-diagnosis patients had a postponed procedure with no rescheduled date. Patients who had a new procedure date waited an average of 61 days for it, while the average wait time for caregivers was 44 days. Although the third survey shows that more procedures have been rescheduled and wait times have decreased, the delays for those who are still waiting remain far too long.

<sup>6</sup> There were only 20 pre-diagnosis patients with a meaningful.

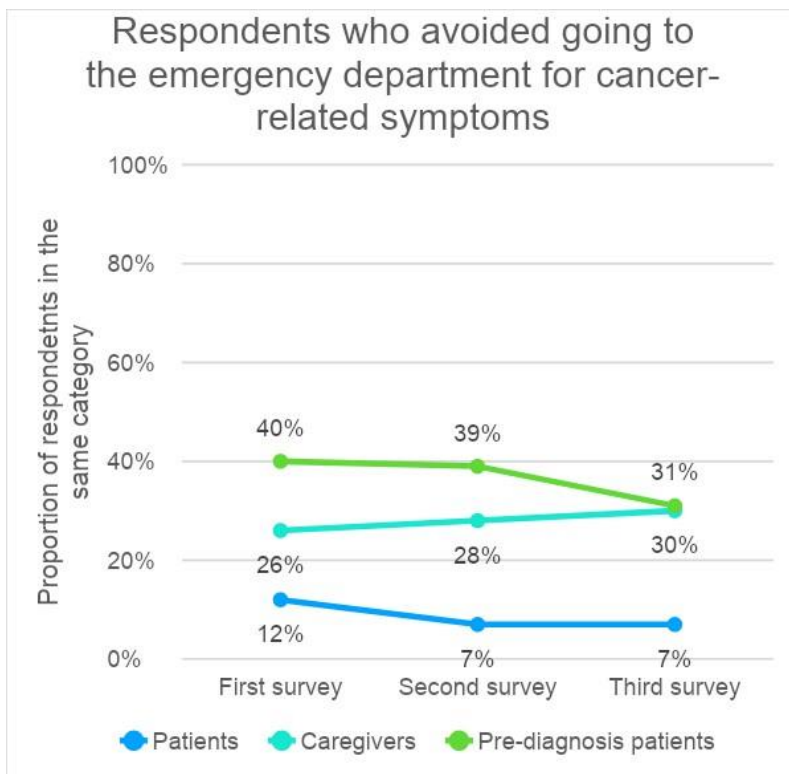


## Fear of healthcare settings

A significant minority of patients and caregivers decided not to seek in-person medical care at some point during the pandemic even when they felt they needed it.

Pre-diagnosis patients and caregivers have both avoided healthcare settings much more than patients.

Pre-diagnosis patients have avoided in-person care the most: just over three in ten had avoided going to the ER during the pandemic for symptoms they thought might be related to cancer. Here the third survey shows a slight decrease from the first two surveys, in which nearly four in ten pre-diagnosis patients in the first and second surveys. Showing a similar downward trend, nearly one in four pre-diagnosis patients in the third survey chose to cancel or postpone an in-person appointment, compared to over one in three in the first survey.



Similarly, one in three caregivers avoided taking the person they care for to the emergency department for cancer-related symptoms. This continues a slight upward trend over the course of the three surveys. On the other hand, a slightly smaller proportion of caregivers in the third survey have cancelled or postponed an in-person appointment compared to the first survey.

Although patients have not avoided healthcare settings as much as caregivers or pre-diagnosis patients, the proportion of patients who have done

so has decreased more. In the first survey, 12 per cent of patients said they cancelled an in-person appointment; the same number avoided going to the emergency department for cancer-related symptoms; and a few more – 13 per cent – did not book an appointment even though they believed they needed one. In the second and third surveys, however, only 5 to 8 per cent of patients did the same.



## Fear of exposure to COVID-19

The most common reasons for avoiding in-person care had to do with fear of contracting COVID-19. Among respondents who did not book an appointment despite feeling they needed one, about one in three patients and three in ten pre-diagnosis patients said they did so because they were concerned that COVID-19 was too prevalent or had similar concerns. Caregivers gave this reason more often.

Hospital visits were a common focus of these COVID-19-related anxieties: some respondents believed that there was a greater risk of infection at hospitals. *“My greatest concern is having to visit the hospital for an appointment or a clinic for tests (bloodwork, MRI, etc.) during the pandemic,”* wrote an Ontario prostate cancer patient, exemplifying this anxiety. *“I am very concerned about going any place where there might be a higher risk of exposure to COVID-19.”*

Others expressed broader concerns, stating that they felt the risk of going outside of their home and being in the presence of other people was just too great. Some simply mentioned *“COVID-19 concerns”* without specifying further.

See the section on “Vulnerability to COVID-19” for more about these anxieties.

## Difficulty booking appointments, concerns about wait times

For patients, the second most common reason for not booking an appointment was that the doctor was too hard to reach or that they were not taking appointments. For caregivers, the next most common reasons had to do with excessive wait times; some specified that they were still waiting for a call from the doctor’s office to schedule an appointment. Pre-diagnosis patients often said, like patients, that the doctor was hard to reach or was not taking appointments, or that they decided they could safely wait since their need for an appointment was not so urgent. Some people may downplay their need for care if they think they are not the ones who need it most and when healthcare resources are constrained.

Respondents often gave combinations of reasons. Explaining why she did not book an appointment, a stage 1 breast cancer patient in Ontario wrote: *“Not sure if they are taking in person [appointments]; too many priorities apart from my health that I know doctors and hospitals are dealing with; want to avoid hospitals as hot spots.”*

## Anxieties and concerns

Although the responses to CCSN's surveys express a wide range of emotions and experiences, there are unmistakable common threads: stress, anxiety about access to cancer care, worry about the state of one's cancer, fear of getting COVID-19, feeling abandoned and lost.

### During the pandemic

The most common concerns patients and caregivers have during the pandemic relate to being able to get medical care in the hospital and getting adequate and timely cancer care.

- Almost **two thirds of respondents** (63 per cent) are concerned about whether they will be able to be cared for in the emergency room if they need it. Just as many (63 per cent) are concerned about being able to get non-emergency hospital care. Significantly more caregivers (77 per cent) and pre-diagnosis patients (77 per cent) were concerned about these issues than cancer patients.
- **Four in five caregivers** (80 per cent) are concerned about the person they care for getting adequate and timely cancer care. This is a significant increase from the first survey, in which two thirds of caregivers (67 per cent) reported this concern.
- A larger percentage of **metastatic (stage 4) cancer patients** than of those at any other cancer stage reported that the pandemic was having a significant effect on their well-being. Three in ten metastatic cancer patients said that they were more afraid for the future during the pandemic, and 32 per cent said that they were afraid that their cancer would progress.

### *Access to care*

The most common concerns when it comes to cancer care during the pandemic, by far, have been about access: whether the healthcare system will be available to patients when they need it. Nearly 50 per cent mentioned access to care when asked about their top concerns related to cancer care during COVID-19, and many others mentioned more

specific concerns within that category – for example, delays in getting care, or whether they would be able to see a doctor in person.

Anxieties about access to care are redoubled because of the urgent nature of cancer care. *“I have been concerned that, should I experience symptoms of relapse,”* wrote a stage 1 ovarian cancer patient in Ontario, *“I would not be able to get in to see my cancer team, or receive the necessary tests in a timely manner, so that if the cancer were rediscovered it would be too far gone to treat.”* Cancer patients are aware of the importance of early detection and treatment and of the potential for the cancer to spread unhindered and unmonitored if treatments or tests are delayed.

### *Cancer coming back or worsening unnoticed*

Cancer patients know that they depend on regular access to cancer care in order to monitor their cancer. Because that access to care has been reduced during the pandemic, many patients and caregivers fear that their cancer could get worse without their knowledge; or, if they are in remission, that their cancer could return unnoticed. Likewise, pre-diagnosis patients fear worse outcomes in case their cancer is diagnosed late.

*“Once you are diagnosed with cancer, even if you are in remission, the fear of getting it again is very present,”* wrote a lymphoma and thyroid cancer patient in Ontario. *“Postponing ultrasounds and biopsies for the lumps I found in my neck has me even more worried. I hope I can have answers really soon. Very stressful times.”*

More than half of all respondents (55 per cent) were concerned about being able to get cancer-related testing during the pandemic. Almost half (49 per cent) were worried about their cancer progressing further during COVID-19.

Over two in five patients (42 per cent) found that the pandemic has caused them to be especially concerned about their cancer progressing. This concern was most prevalent among women and recently diagnosed patients who were diagnosed less than two years ago.

Although these concerns appeared frequently across the board, they are most common for caregivers. Almost three in four caregivers (74 per cent) were concerned about the ability of the person they care for to get cancer-related tests during the pandemic. A

similar proportion of caregivers (73 per cent) were especially worried during the pandemic about their loved one's cancer progressing.

	Patients	Caregivers	Pre-diagnosis patients
Concerned about being able to get cancer-related tests during the pandemic	50%	74%	56%
More fearful of cancer progressing because of the pandemic	42%	73%	65%
Worried about ability to get timely cancer care (or plan for it)	54%	77%	64%

Likewise, many people awaiting a potential cancer diagnosis worry that if they do have cancer, it will not be caught in time to respond optimally. *“Having the doctors postpone and cancel my appointments and treatments makes me a bit worried,”* said an Ontario pre-diagnosis patient, *“because I’m scared it might spread during the time being without my noticing.”*

More than half (56 per cent) of pre-diagnosis patients surveyed were anxious about getting tests to confirm their diagnosis in a timely fashion. More than two out of three (64 per cent) were worried about treatment planning if they are diagnosed with cancer. A similar proportion (65 per cent) were more worried because of the pandemic about their cancer progressing.

An Ontario breast cancer survivor shares this concern, empathizing with pre-diagnosis patients. *“When I was first diagnosed (non pandemic),”* she wrote, *“I had surgery within one week, dense dose chemotherapy, and extensive radiation. I appreciate how very fortunate I was, and if my treatment plan had been delayed, I suspect my survival would not have been assured, so I am very concerned about any new patient who may be in a similar situation at this current time.”*

## *Vulnerability to COVID-19*

Because cancer patients often have compromised immune systems, infectious diseases are more of a concern for them than for most people – a source of stress even outside of a global pandemic. *“My immune [system] is compromised, even long after the chemo,”* wrote a stage 4 leiomyosarcoma patient in British Columbia, *“so I am more concerned about going out to the grocery store, or just on walks, due to fear of infection.”* Contracting COVID-19 and becoming ill or dying is therefore another prominent subject of respondents’ fears.

Healthcare settings – and hospitals in particular – emerged as a focus of these anxieties: many respondents are especially concerned about the risk of exposure to COVID-19 at these places. *“I was extremely worried that my daughter-in-law might contract COVID during the weekly trips to the hospital,”* wrote a caregiver for a stage 1 breast cancer patient in Ontario, who was also *“worried about short staffing and possibility of cancelling procedures and surgery.”* In this vein, fears of contracting COVID-19 at a hospital seem to overlap, for some respondents, with concerns that hospitals are being overwhelmed generally by the pandemic.

Feeling caught between fear of COVID-19 on the one hand and anxiety about one's cancer on the other is another common theme. *“It concerns me to go to a doctor's office or hospital due to being immune-compromised,”* a breast cancer patient in British Columbia wrote, *“and therefore I have had more anxiety about where my cancer is at and about not catching the spread of cancer (if it occurs) in a timely manner.”* For patients worried about contracting COVID-19 at a hospital, the situation is stressful no matter what they do – whether they in fact go to the hospital or opt to stay home.

Patients and especially caregivers are acutely aware that they should not delay going to the hospital for reasons related to their own or their loved one's cancer. The real source of stress for cancer patients and caregivers is not just fear of exposure to COVID-19, but the tension between this fear and the necessity of timely medical care.

*“It is stressful,”* wrote a caregiver for a prostate cancer patient in Ontario, describing this tension. *“I worry about him going to appointments, but I also worry about skipping appointments. There needs to be a way to provide care and go the extra length to minimize any risk of COVID-19 transmission too.”*

## As the pandemic subsides

### What are cancer patients most worried about once COVID-19-related restrictions are lifted?

As survey respondents look ahead to the end of the pandemic and the lifting of public health restrictions, they see themselves having mostly the same concerns as during the pandemic. For cancer patients, the top concerns for after restrictions are lifted have to do with having access to healthcare when they need it.

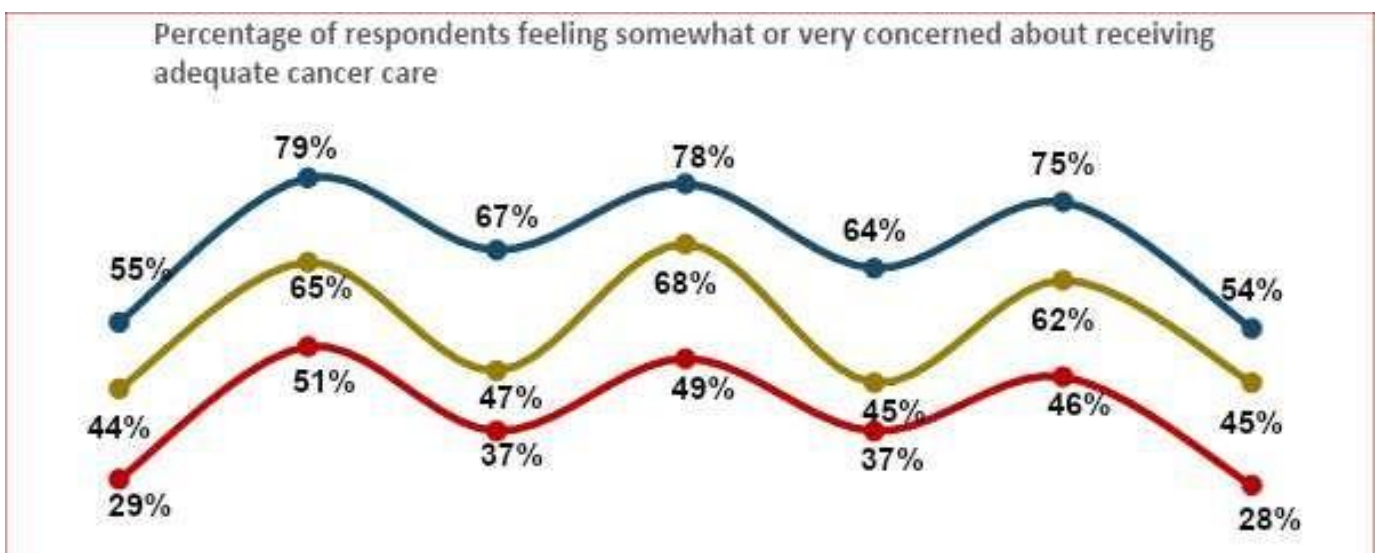
In the second survey, concerns about access to hospital care were most common across the board – 36 per cent of patients, 64 per cent of caregivers, and 56 per cent of pre-diagnosis patients were concerned about being able to get hospital or ER care. In the third survey, however, these concerns declined slightly in importance, and receiving timely cancer treatment became the most prevalent topic of concern for patients, caregivers, and pre-diagnosis patients alike. This suggests that cancer patients have become somewhat more confident in the ability of hospitals and cancer centres to manage COVID-19 cases and keep other patients safe.

For caregivers, being able to get help for side effects and being able to receive post-treatment rehabilitative care were also important concerns.

## Change over time

### How has cancer patients' anxiety about getting adequate cancer care changed over the course of the pandemic?

When respondents compared their current level of anxiety about their cancer care with how anxious they felt in previous stages of the pandemic, a clear pattern emerged. In

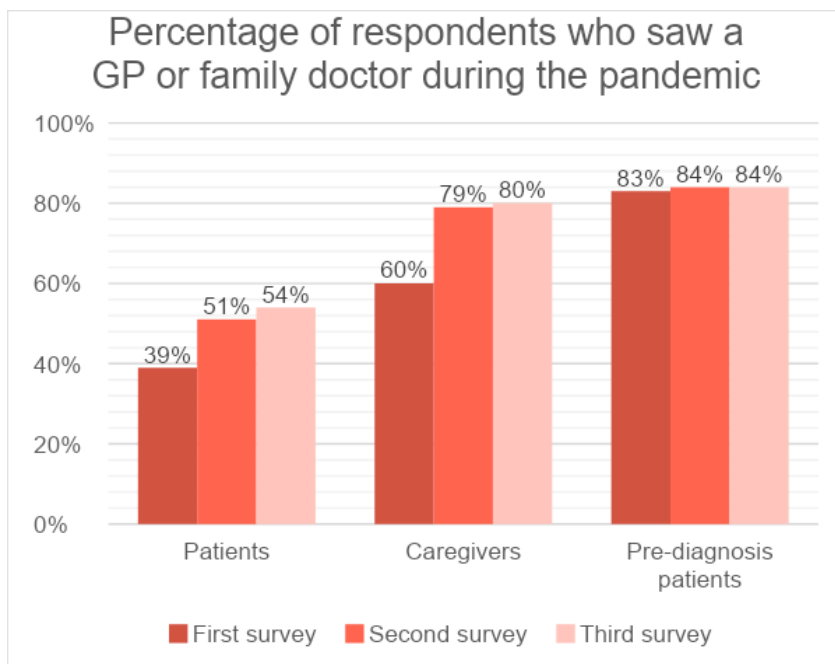


each of the three waves of the pandemic thus far, a high proportion each of patients, caregivers, and pre-diagnosis patients felt anxious about being able to receive adequate cancer care; fewer felt anxious in the periods between the waves; and a lesser proportion yet felt anxious about their cancer care before the pandemic and after the third wave.

On the one hand, it is not surprising that the intensity of the pandemic and the way it has been divided into “waves” are reflected in the anxiety levels of cancer patients. On the other hand, it is notable that the same proportion of respondents feel anxious about cancer care after the third wave of the pandemic as recall feeling anxious before the pandemic began. This hardly means that cancer patients are at ease – 28 per cent of patients, 54 per cent of caregivers, and 45 per cent of pre-diagnosis patients represent a large number of people. If anything, it is troubling that so many patients and caregivers recall feeling worried about their cancer care before COVID-19 was a household name.

## Interactions with physicians

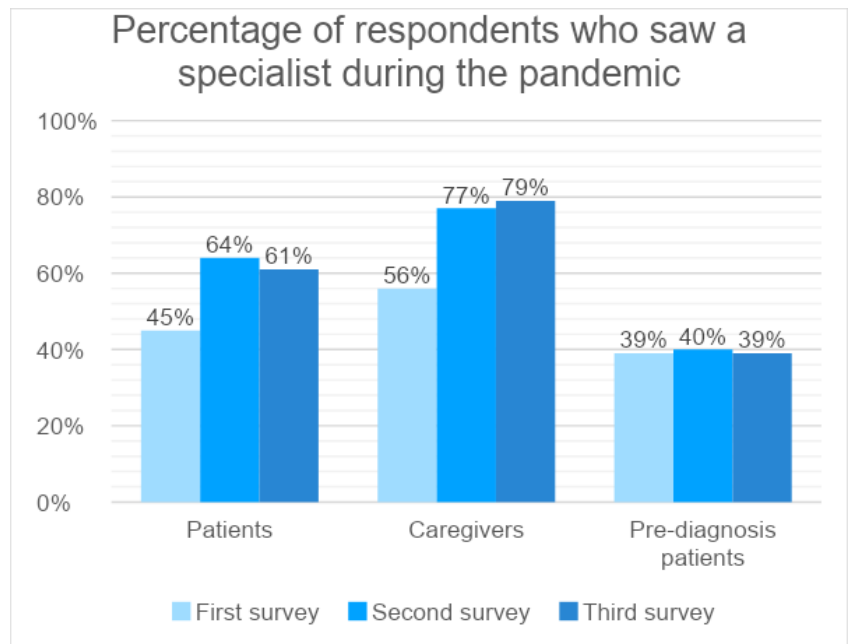
### What kinds of healthcare professionals have patients seen?



More than half of patients (54 per cent) have interacted with a GP during the pandemic, and 61 per cent have seen a specialist. Caregivers have shown an especially high level of engagement with healthcare professionals: four in five (80 per cent) have seen a GP, and nearly as many (79 per cent) have interacted with a specialist. More than four in five pre-diagnosis patients (84

per cent) saw a GP during the pandemic, while 39 per cent have interacted with a specialist.

Many more cancer patients and caregivers interacted with physicians in the second and third waves of the pandemic than in the first wave. Sixty-four per cent of patients and 77 per cent of caregivers in the second survey had seen a specialist, compared to 45 per cent of patients and 56 per cent of caregivers in the first survey – jumps of 19 and 22 percentage points respectively. The proportions of patients and



caregivers who interacted with GPs showed similarly large changes. The changes between the second and third surveys were less significant. Pre-diagnosis patients, on the other hand, have changed by no more than a percentage point since the first survey.

Earlier in the pandemic, more patients and caregivers were interacting with specialists than with GPs, but as of the third survey they are seeing both with equal frequency. Pre-diagnosis patients, on the other hand, have seen GPs much more and specialists much less; this makes sense, given that they do not have a cancer diagnosis yet.

## How have patients communicated with healthcare professionals?

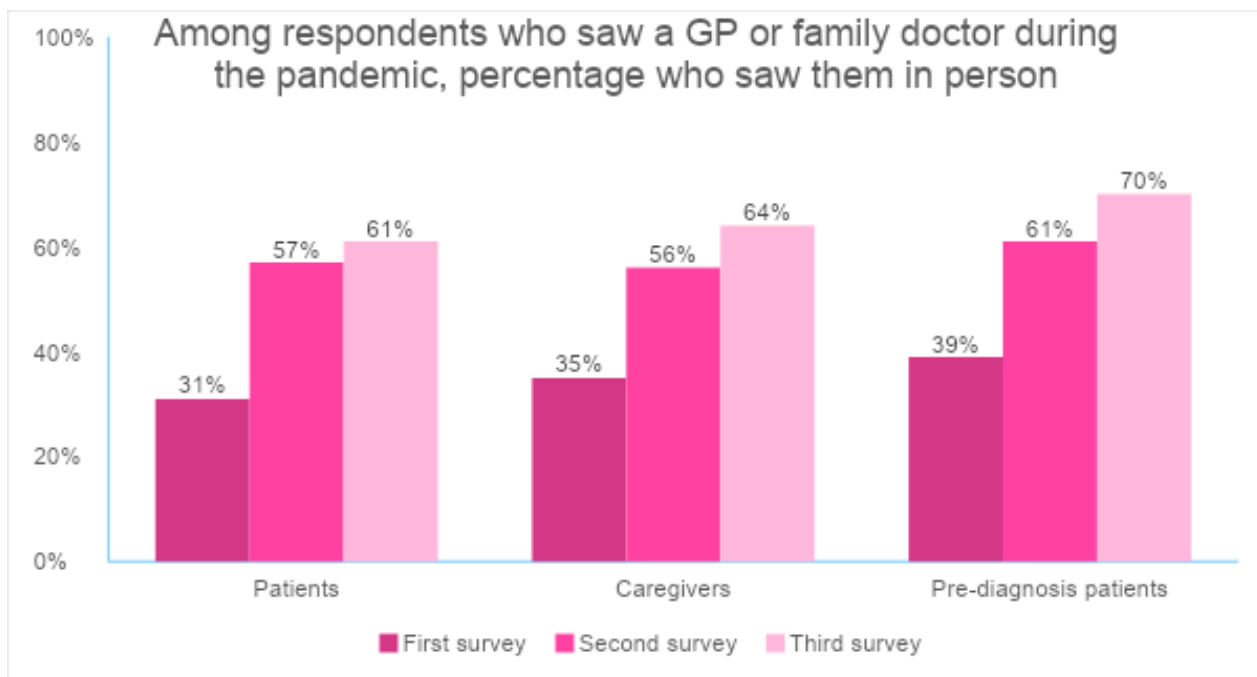
Although video calling has soared in popularity in general during the pandemic, telephone calls remain the most used method of communication for cancer care. Most interactions that survey respondents had with a health care professional during the COVID-19 pandemic took place over the phone. In-person interactions came in second: among patients, caregivers, and pre-diagnosis patients who saw a GP during the pandemic, three in five did so in person. Fewer still had appointments over video call, or communicated by email, instant messaging, or text message.



Compared to video calling, phone calling has the advantages of simplicity, reliability, and familiarity. Not everyone is comfortable with video calling software, and many do not have a device capable of making video calls.

### *Change over time*

Early in the pandemic, in-person appointments were much less common: only one in three patients who had interacted with a GP in the first survey had done so in person, and likewise for 35 per cent of caregivers and 39 per cent of pre-diagnosis patients.



(In-person interactions with specialists were similarly uncommon.)

By December 2020, this had changed. More than half of patients, caregivers, and pre-diagnosis patients in the second survey had seen a physician in person during the pandemic. As in the first survey, in-person visits with GPs were not significantly more or less common than with specialists. The third survey, by comparison, showed only a slight increase in in-person visits.

### *Satisfaction with change to remote appointments*

Patients and caregivers seem to be largely comfortable with switching from in-person to telephone appointments, although in-person appointments are usually preferred. For some, though, the lack of in-person contact is a source of stress.

Among patients who had a phone appointment with a GP during the pandemic, 85 per cent were happy with how it went, compared to 97 per cent of patients who had an in-person appointment. Although fewer caregivers overall were satisfied with their interactions with physicians, their relative preference for in-person appointments was similar to that of patients. Nearly four in five caregivers (79 per cent) who had a phone appointment with a GP were satisfied with how it went, while about nine in 10 caregivers<sup>7</sup> were satisfied with their in-person appointments.

However, some patients find it harder to communicate over the phone or on video. *“I find phone conversations difficult, video call better, but not optimal,”* said Carol, a stage 4 patient in Ontario with multiple cancers. *“Very much miss in person appointments, body language, reading between the lines so important.”*

Another patient, with stage 1 thyroid cancer, finds that telephone conversations, although safer, *“are not very effective for communicating symptoms and examining changes to health.”* Fewer patients have been in contact with their healthcare providers primarily by email. *“I really miss the personal contacts with my oncologist,”* wrote a B.C. lymphoma patient. *“Things come up in a conversation which are helpful and calming. I have not seen him in four to five months and just communicate by email. I feel a bit ‘in the dark’.”*

Other patients point out that there is sometimes no substitute for having a doctor look at your body with their own eyes. Some are anxious that things that would have been caught by a physical examination have been missed in phone or virtual appointments – signs that an active cancer is getting worse, or that a cancer in remission is starting to recur.

*“Due to COVID-19, my scheduled exam was changed to a phone appointment. I took pictures of the affected areas and emailed to the doctor. Likely the best choice given the pandemic, but I would have preferred the physically present exam I would normally get. In the past the exam has caught other spots in the pre-cancerous stage, and I received treatment for them immediately. Without the exam, I have no certainty that other areas on my body are not exhibiting pre-cancerous conditions.”*

Hilde, an Ontario anal cancer patient who is in remission, experienced these anxieties: *“I had a virtual appointment with my radiation oncologist. This heightened my anxiety as I*

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<sup>7</sup> 91 per cent in the second survey; 89 per cent in the third.

*was not able to have a physical exam. As the days pass, I experience anxiety close to panic attacks at times thinking I may have a recurrence that has been missed because of the virtual appointment. ... Pre-COVID I felt that I had much better care."*

On the whole, far fewer respondents were unhappy with the lack of in-person appointments than were concerned about the risk of contracting COVID-19 in a hospital (or of their loved one contracting it, in the case of caregivers). A few caregivers even expressed relief at not having to take the person they care for to the hospital, because phone or virtual appointments were available.

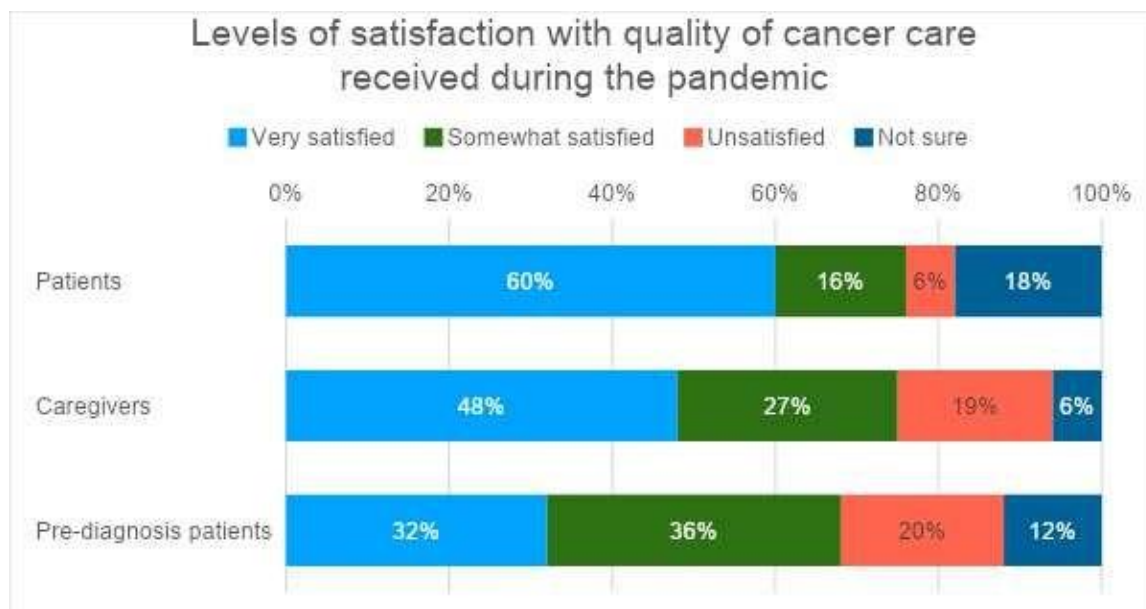
## Satisfaction with quality of care

Respondents' levels of satisfaction with the quality of their cancer care (or that of the person they care for) basically reflect how much they were affected by the general interruptions to cancer care because of the pandemic. Although some were dissatisfied because of reasons unrelated to COVID-19 – for example, because they felt the doctor's office was disorganized – these reasons were in the minority.

Delays in getting care, cancelled appointments, and unavailability of in-person appointments were the most common sources of dissatisfaction with the quality of care. Lack of communication was also a persistent theme. For one stage 4 breast cancer patient in Ontario, *"not having in person doctor visits"* and *"long wait times for scans and tests"* were reasons for feeling unsatisfied with the quality of care. Lack of communication was also a persistent theme: *"The communication between all of my doctors isn't there like before,"* wrote the same breast cancer patient; *"[I am] feeling like I have fallen between the cracks."*

*"I did not, nor am I now receiving any rehab help with my chemo side effects from my cancer team,"* wrote a stage 4 colorectal cancer patient in Ontario, expressing similar difficulties with communication and feelings of being uncared for. *"It's been next to impossible to get hold of any of them on the phone. I feel neglected by them."*

Respondents who were satisfied with their care, on the other hand, gave reasons such as confidence in their doctor, availability of the doctor, and that the necessary care (appointments, surgeries, etc.) took place.



As with other questions, there is considerable variation between patients, caregivers, and pre-diagnosis patients. About six in ten patients in all surveys were very satisfied with the quality of their care. Caregivers tended to be less happy with the cancer care given their loved one, but significantly more caregivers said they were “very satisfied” in the third survey (almost five in ten) than in the second (almost four in ten). Only 32 per cent of pre-diagnosis patients were “very satisfied” with their care during the pandemic.

Caregivers showed the most obvious change in their levels of satisfaction: in the third survey 48 per cent said they were “very satisfied” with the cancer care that the person they care for received, up from 39 per cent in the second survey. By that measure, patients and pre-diagnosis patients showed virtually no change.

These results show that pandemic-related problems accessing cancer care have eclipsed the nature of the care itself as the main driver of patients’ and caregivers’ feelings about their own or their loved one's cancer care.

## Clinical trials

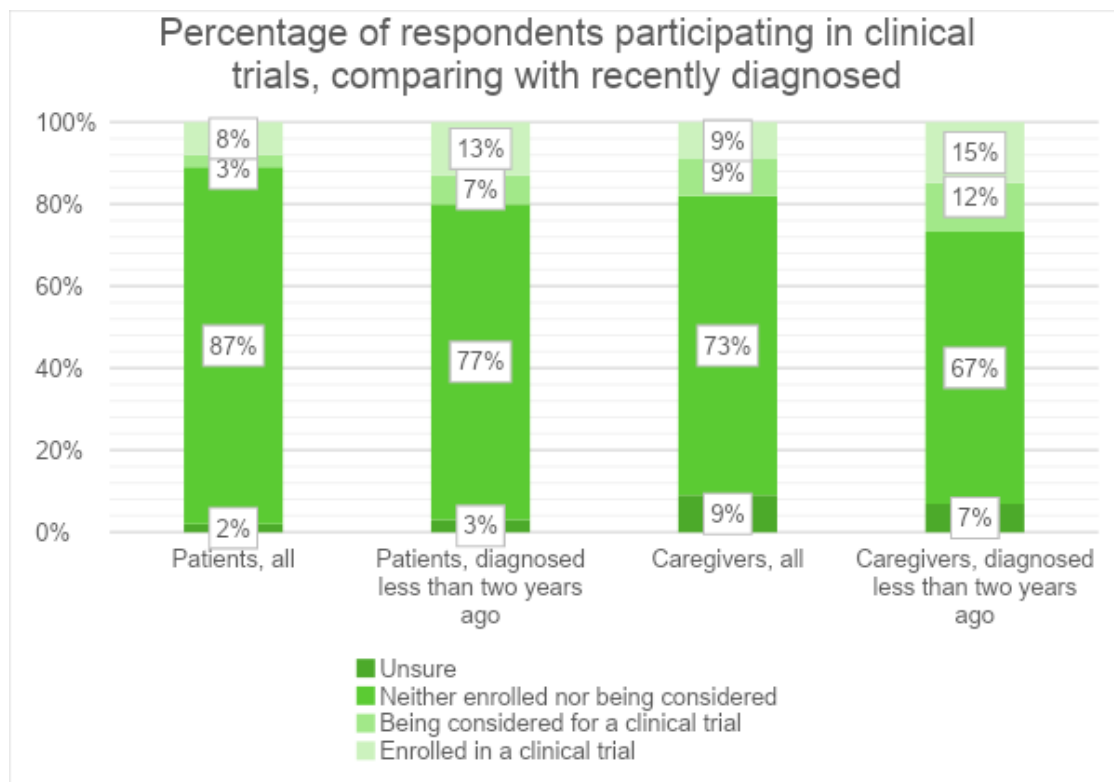
*How has the COVID-19 pandemic affected cancer-related clinical trials? Has it made it harder for people to continue participating? Has it caused trials to stop or be put on hold?*

Although only a fraction of cancer patients participate in them, clinical trials for cancer treatments are vitally important, both for their research outcomes and, often, for the

patients involved. New treatments to which patients have access through clinical trials may turn out to be more effective or have fewer side effects for them than the standard of care. CCSN's surveys suggest that many trials have either been put on hold or stopped entirely during the pandemic, but in cases where clinical trials continued, nearly all patients who were participating chose to stay on.

### *How many respondents were participating in clinical trials?*

Overall, just under one in five caregivers (17–18 per cent across all surveys) were responding on behalf of someone who was participating in a clinical trial.<sup>8</sup> A smaller proportion of patients – ranging from five to 11 per cent across all surveys – were clinical trial participants.



In the first survey only, clinical trial participants tended to be recently diagnosed: 57 per cent of respondents enrolled in or being considered for a clinical trial were diagnosed with cancer less than two years ago, and 23 per cent were diagnosed between two and five years ago.

<sup>8</sup> For simplicity and brevity, respondents who were either enrolled in or being considered for a clinical trial are grouped together in this report as clinical trial participants. This is mainly because subsequent questions in the survey about the status of the clinical trial were directed toward this subgroup.

### *Have participants withdrawn from their clinical trials or stayed on?*

Nearly all respondents who were involved in a cancer-related clinical trial when the pandemic began chose to continue their involvement when it was possible. In all surveys, about half of respondents who were participating in a clinical trial said that the trial was ongoing and that they were continuing to participate. For most respondents who were no longer participating, either the trial had been halted or put on hold, or they were not aware of its status.

Of the few people who did not continue participating even though the trial was continuing, almost all were living in rural rather than urban areas. Clinical trials usually take place in cities, so people living in rural areas would have to travel to participate. In some cases, rural participants might be reluctant to drive into cities where COVID-19 was more prevalent, or transportation might be unavailable or logistically difficult because of pandemic-related restrictions.

## **COVID-19 vaccination**

Although cancer patients have not fared well overall during the pandemic, they are doing better than other Canadians when it comes to COVID-19 vaccination: rates of vaccination are higher and vaccine hesitancy is rarer.

Questions about COVID-19 vaccination were added in CCSN's third survey. The results showed that a remarkable 93 per cent of patients said they had received at least one dose of a COVID-19 vaccine. For pre-diagnosis patients, the rate was 84 per cent. Caregivers were asked separately about vaccination for themselves and for the person they care for: 83 per cent of caregivers had received a vaccine themselves, and 77 per cent said the person they cared for had received one.

These vaccination rates for cancer patients and caregivers were all significantly higher than the national rate at the time the third survey was taken. On July 3rd, 2021, just over two thirds of Canadians – 68 per cent – were at least partially vaccinated. This shows that not only cancer patients but also caregivers and people waiting for a possible diagnosis were ahead of the curve when it comes to COVID-19 immunization.

*Now [that] I've had both my vaccines, I'm feeling much less fearful. —A  
stage 2 endometrial sarcoma patient in British Columbia*

Immunization rates in the wider population still need to increase for cancer patients to be protected and feel at ease, however. Seven per cent of patients said they would be more comfortable going to the hospital, whether for cancer care or for other reasons if more people were vaccinated against COVID-19. Some specified that hospital staff or other patients should all be vaccinated; others simply wanted more people to be vaccinated overall. A few mentioned that they were no longer concerned about going to the hospital because they were fully vaccinated.

Reluctance or unwillingness to get vaccinated is fairly uncommon among respondents: only six per cent, or just over one in 20 – said that they do not plan to get vaccinated. Although not ideal, this is a lower rate of vaccination hesitancy than for Canada as a whole. A [survey of 1000 Canadians by Ipsos](#) in June 2021 found that 18 per cent of respondents were hesitant to get vaccinated for COVID-19. That includes nine per cent who were unsure and nine per cent who said they would never get the shot.

The Ipsos survey also found that younger people were more likely to be hesitant to get vaccinated. The respondents of CCSN's survey, on the other hand, tend to skew older, with an average age of 65. This may partly explain why fewer cancer patients seem to be vaccine-hesitant compared to the overall population.

Those few cancer patients who don't plan to get vaccinated do not seem to have uniquely cancer-related reasons for their reluctance. When asked to comment on why they didn't plan to be vaccinated, respondents mostly wrote that they didn't trust the vaccine, were worried about side effects, or felt they didn't need it. These are essentially the same reasons reported by vaccine-hesitant respondents to the Ipsos survey. Only one respondent mentioned cancer as part of their reason.

### *Key takeaways*

Cancer patients, cancer caregivers, and pre-diagnosis patients across Canada recognize the importance of vaccination as a public health measure to curb the spread of COVID-19 and hasten the end of the pandemic. Getting as many patients, caregivers, and health care workers fully vaccinated as possible is essential for cancer patients' safety and mental well-being.

## Financial impact

Financial struggles are nothing new for cancer patients. Household incomes for cancer patients are 26 per cent lower than for the general population. The total wages lost for patients and caregivers on account of cancer in 2009 are estimated at \$3.18 billion.<sup>9</sup> On top of lost income, cancer also creates additional expenses. Although Canada's healthcare system ensures that no one has to pay for hospital care, cancer patients often must pay out of pocket for drugs, homecare, and medical devices, for example. Travel and parking costs to get to treatment locations can also be financially burdensome. A 2021 study of 901 Canadian cancer patients found that one in three patients experienced a high financial burden from cancer care; on average, these patients spent 34 per cent of their monthly income on expenses related to cancer care.<sup>10</sup>

The pandemic has compounded these struggles. Cancer patients, caregivers, and pre-diagnosis patients are far from the only ones who have suffered financially during the pandemic, but because their financial situations were often more fragile to start with, the net result can be even worse.

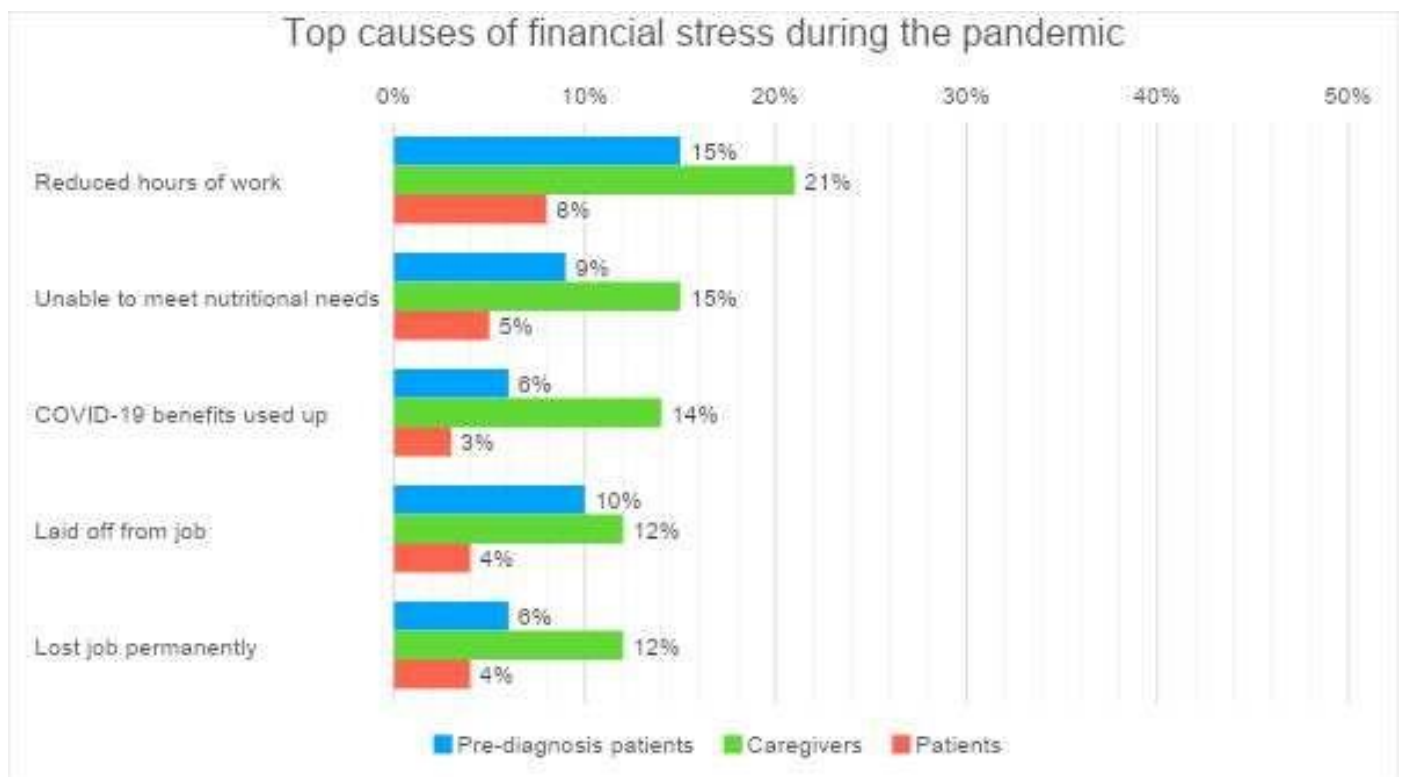
One in ten respondents had reduced hours of work because of the pandemic – this was the most frequently mentioned cause of financial difficulty. Additionally, almost six per cent were laid off from their job.

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<sup>9</sup> Hopkins, R.B.; Goeree, R.; Longo, C.J. Estimating the National Wage Loss from Cancer in Canada. *Current Oncology* **2010**, 17, 40-49. <https://doi.org/10.3747/co.v17i2.477>

<sup>10</sup> Longo, C.J., Fitch, M.I., Loree, J.M. *et al.* Patient and family financial burden associated with cancer treatment in Canada: a national study. *Supportive Care in Cancer* **29**, 3377–3386 (2021). <https://doi.org/10.1007/s00520-020-05907-x>





Patients or caregivers who have lost their jobs or worked fewer hours because of the pandemic are even less able to manage extra cancer-related expenses and have a harder time making ends meet in general. Seven per cent of all respondents – or about one in 14 – had trouble meeting their nutritional needs because of the financial strain.

Caregivers indicated an adverse financial impact more than other respondents. Over half of all caregivers (52 per cent) said that the person they care for experienced some kind of financial impact because of COVID-19. Just over one in five (21 per cent) had fewer hours of work, and 15 per cent have had difficulty meeting their dietary requirements.

## Highlighted groups

### Caregivers

#### *Disruptions to cancer care*

Caregivers have been hit hardest by every kind of disruption to cancer care. Delays in appointments, screenings, and tests have affected far higher proportions of caregivers than of cancer patients or pre-diagnosis patients. Compare the 42 per cent of caregivers

who have had in-person appointments for their loved one delayed to the 23 per cent of patients and 25 per cent of pre-diagnosis patients who have experienced this, or the 34 per cent of caregivers who have had their loved one's cancer-related test cancelled or rescheduled to the corresponding 11 per cent of patients.

When it comes to cancer treatment, the differences are even more striking. Compared to patients, more than four times the percentage of caregivers (31 per cent compared to seven per cent) have had scheduled procedures postponed or cancelled. More than one in four caregivers (28 per cent) say that the person they care for has not been able to start or continue their cancer treatment that requires visiting a clinic or hospital, and over one in five (21 per cent) have not been able to fill a prescription for cancer treatment on time: by contrast, only three per cent of patients have experienced these difficulties.

### *Mental health impact*

Anxiety and stress have consistently been much more prevalent among caregivers than among patients or pre-diagnosis patients. Four in five caregivers responding to the second and third surveys (81 per cent) found that COVID-19 pandemic had significantly raised their levels of anxiety, and close to three in four (72–73 per cent) say it has adversely affected their mental health. Compare this with the 50 per cent of patients and 66 per cent of pre-diagnosis patients whose anxiety has increased during the pandemic: such great differences are typical across the board.

Feelings of uncertainty, a sense of lack of control, and worries about cancer spreading undetected are topics caregivers mention frequently as sources of anxiety. *“The postponed appointments and treatments which my father has encountered has been a weight on my mind,”* wrote a caregiver for a liver cancer patient in Ontario. *“I wonder if the postponements or delays will cause the cancer to return or to spread to other parts of his body. I wonder how he is feeling about the situation which is really beyond his control.”*

Why do caregivers tend to be more anxious? One reason may have to do with the caregiver's role in ensuring their loved one receives the care they need. Many caregivers take on a great deal of responsibility for the cancer care of the person they care for, and often act as the navigator between the patient and the cancer care and healthcare systems. Most assist them by, for example, attending their appointments (61 per cent),

driving them to appointments (83 per cent), or participating in medical treatment decisions or discussions (63 per cent). About four in five caregivers have interacted with specialists or GPs during the pandemic. It can be easy to feel more anxious about someone for whose care one is responsible than one would for one's own sake.

### *Accompanying to appointments*

Some caregivers are dismayed that COVID-19 restrictions prevented them from accompanying the person they care for at in-person healthcare settings. In the third survey, 13 per cent of caregivers expressed this kind of concern.

Caregivers can find it difficult to be unable to support the person they care for and ensure that their needs are met while in the hospital. A caregiver for their spouse, a metastatic sarcoma patient in British Columbia, found it *“very heartbreaking and stressful”* to be unable to visit their spouse in the hospital. A caregiver for a myeloma patient in Manitoba was glad to be able to *“attend the chemotherapy session with my mom”* and to *“sit with her and be her distraction,”* but *“at times,”* the caregiver wrote, *“the front [desk] will not let me go to the lab with her ... It gets frustrating.”*

Other caregivers are concerned that the person they care for may die while in the hospital without being able to see them. *“His cancer is not treatable, he was not given long to live, and if he is in the hospital when he passes away, the family won't be able to be with him,”* wrote a caregiver for an Ontario liver cancer patient.

The role caregivers play at appointments can also be more practical – for example, remembering or recording important details and ensuring that the patient and doctor are communicating effectively. *“It has been difficult to get information, and no one was allowed to enter the hospital with him during COVID,”* wrote a caregiver for a prostate cancer patient in Alberta, *“and Dad was often very confused at his appointment and unable to relate what was said back to us from the doctors after the appointments.”*

Another caregiver, who cares for a colorectal cancer patient in Alberta, points out that if a medical appointment is a stressful environment for a patient, it is even more important for their caregiver to be there to take notes. *“I have been restricted from attending the in-person appointments. This is concerning,”* the caregiver wrote, *“due to the patient not being able to either understand or remember information/instructions given during the appointment. When a person is under stress, the less they remember.”*

Many caregivers help the person they care for navigate the healthcare system, ensuring that the patient's needs are clearly communicated to their doctors and that the doctors' instructions and advice are understood and implemented. When caregivers are not able to attend appointments, there is a risk that the person they care for may not receive the care they should. At best, it causes stress for the caregiver as they try to make sure that nothing has been missed.

## Lung cancer patients

Anxiety about getting COVID-19 and feelings of acute vulnerability appeared frequently in the responses of lung cancer patients and caregivers. *"I worry that either I or my husband will get the COVID virus and because of his health, he might not survive,"* wrote a British Columbia caregiver for her husband, who has multiple types of cancer, including lung cancer. *"All the worry, pain, time, effort to recover might be in vain if he gets sick with COVID."*

These worries have a basis in reality. Lung cancer patients who contract COVID-19 have been found to be more likely to have a more severe form of the disease, and more likely to die from it, compared both to patients with other types of cancer and to the general population.

The COVID-19 and Cancer Consortium (CCC-19) has found that lung cancer patients have the highest morbidity rate of all cancer patients who contract COVID-19, at 26 per cent – compared to 16 per cent for cancer patients overall (within a median follow-up period of 30 days). The CCC-19 is a consortium of over 120 cancer centres and organizations in the United States that collects international data on cancer patients who have been diagnosed with COVID-19. A study of 102 lung cancer patients diagnosed with COVID-19, published in June 2020, found a similar result: of the patients studied, 25 per cent died within the study period.

Like others living with cancer or caring for someone with cancer, many lung cancer patients and caregivers worry about in-person appointments. They fear that in-person appointments may expose them to the virus, especially if they or the person they care for is older. *"I'm concerned [my mother will] get the coronavirus and also could pass it to my dad who is 80,"* a caregiver for a lung cancer patient in Ontario wrote. *"She had to go to a busy hospital for updated scans and she did say it was run very well but it's still worrying."*

Percentage of respondents who are ...	Lung cancer patients	Lung cancer caregivers
First survey	8%	19%
Second survey	8%	17%
Third survey	6%	11%

More than one in twenty patients who responded to CCSN's third survey have lung cancer, and over one in ten caregiver respondents are caring for someone with lung cancer. (Many of these patients have other types of cancer as well.) The first survey had a greater proportion of respondents with lung cancer, which decreased in the subsequent two surveys.

## CCSN's pan-Canadian *Cancer Can't Wait* Virtual Action

### Weeks

CCSN continues to raise awareness about COVID-19 disruption of cancer care in Canada by sharing the results of our Leger surveys on COVID-19 cancer disruption of cancer care through media and with politicians and other decision makers across this country.

CCSN asked politicians and decision makers not to wait until the pandemic is declared over to invest in strengthening cancer screening and cancer care. We all know that **Cancer Can't Wait** for those who are without a cancer diagnosis due to screening delays and for those whose cancer may have progressed to a later stage during the pandemic. CCSN asked politicians and decision makers to remember that delays will undoubtedly result in an increase in the number of deaths from cancer. CCSN also asked governments to update and strengthen their pandemic and natural disaster plans to prioritize cancer care during any future pandemics or natural disasters.

CCSN would like to offer its sincere thanks and appreciation to the cancer patients, caregivers, and survivors whose testimony about the impact of COVID-19 on their lives brought home the reality of having cancer during the pandemic.

## Conclusion

It is critical to plan for continued cancer care during future pandemics as well as other crises that may affect Canada, including civil unrest, environmental disasters, or economic hardships. Safe and timely access to essential cancer care — including diagnostics, testing, and treatment — must remain a top priority across Canada during any crisis.

Preparations can't wait. Cancer can't be delayed or postponed. We have no way of knowing the timing or nature of Canada's next major crisis. But the responsibility to help tomorrow's patients and caregivers has to start today.