

For Cancer Patients and Caregivers, the Pandemic is Not Over

COVID-19 concerns persist as Canadian society re-opens



Canadian Cancer Survivor Network
4th Survey Report
www.survivornet.ca

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Executive Summary

Circumstances have changed dramatically since the COVID-19 pandemic reached Canada in the spring of 2020. New and highly transmissible variants have emerged; public health restrictions have been loosened; and COVID-19 has become more prevalent than ever.

In late spring 2022, the Canadian Cancer Survivor Network (CCSN) commissioned a Leger survey to find out how cancer patients and caregivers are coping at this point in the pandemic. This research is the fourth in CCSN's series of Leger surveys examining the impact of the COVID-19 pandemic on cancer patients and caregivers. The results showed that:

- **Contracting COVID-19** is cancer patients' and caregivers' top concern.
- **Lifting public health restrictions has put cancer patients at risk.** Restrictions designed to prevent the spread of COVID-19 were seen by many patients and caregivers as important protective measures. Half of respondents are uncomfortable with the lifting of restrictions.
- **Access to healthcare remains a concern.** Fifty-one per cent of respondents are concerned about whether they can get timely cancer care, compared to 42 per cent in CCSN's previous survey.
- **Masks are perceived as important.** Patients and caregivers think masks are an easy and effective way to help keep themselves and others safe. Most plan to continue wearing masks for the foreseeable future.
- **Immunocompromised cancer patients and caregivers** are especially concerned about the risk of COVID-19 infection during everyday activities in public and during hospital visits.
- **Hospitals are seen as places with an elevated risk of COVID-19 transmission.** Half of patients and caregivers are not comfortable visiting a hospital to receive cancer care.

Cancer patients cannot ensure their safety from COVID-19 and their access to care alone: they depend on governments, healthcare systems, and the general public. Not only during the current pandemic, but also in case of future threats to cancer patients' safety and access to care, the needs of cancer patients must be considered from the start. Cancer can't wait!

About the survey

The 15 minute online survey was conducted by Leger from April 13 to May 12, 2022. The respondents included 1,100 patients and 253 caregivers for a total of 1,353 respondents, all of whom were recruited from Leger's LEO survey panel. All respondents were at least 18 years of age and living in Canada.

CCSN's previous surveys with Leger on the impact of the pandemic on cancer patients in Canada were conducted in May–June 2020, December 2020, and June–July 2021. These first three surveys focused on problems with access to cancer care during the pandemic and on patients' and caregivers' concerns about access to care. Although this survey has much in common with its three predecessors, it focused primarily on cancer patients' and caregivers' concerns about COVID-19 itself and public health approaches to the disease.

[Comprehensive information about all four surveys](#) is available on CCSN's website, including webinars, slides, media releases, and a report on the first three surveys.

About the Canadian Cancer Survivor Network

CCSN works to connect patients, survivors and other stakeholder groups with decision makers and the wider community to engage in discussion and to act on evidence-based best practices to alleviate the medical, emotional, financial, and social costs of cancer. To learn more, visit www.survivornet.ca.

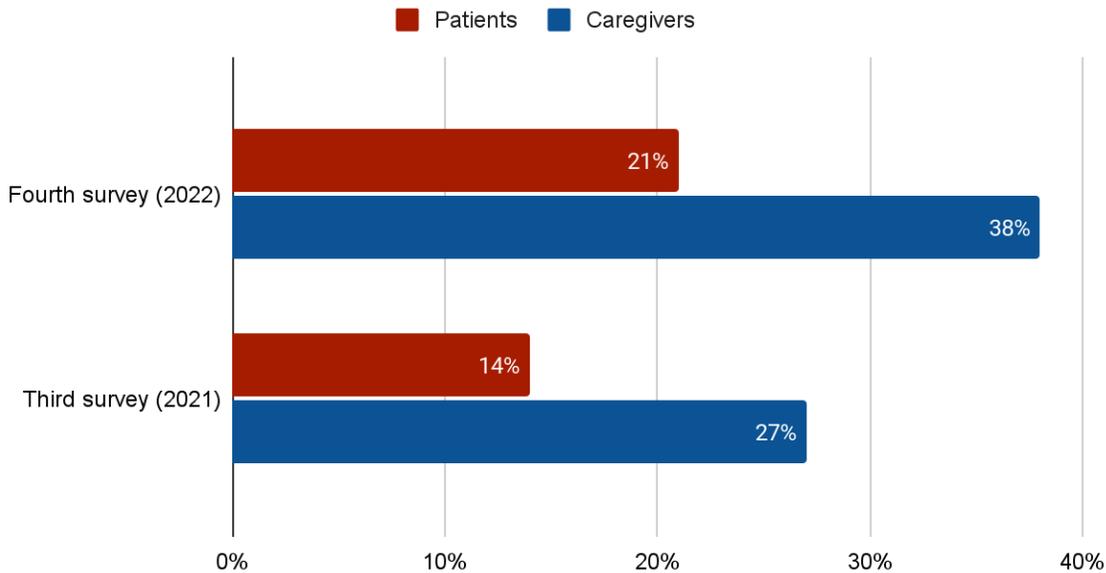
Fear of getting COVID-19

“The COVID pandemic is NOT OVER and we are all pretending like it is. There is a 6th wave happening and it seems as if no one cares that the immune-compromised are still at risk.”

— A caregiver for a stage 4 lymphoma patient in British Columbia

The risk of getting COVID-19 is the top concern of cancer patients and caregivers at this point in the pandemic. Concerns about the risk of getting COVID-19 dominated the answers to the open-ended survey questions. CCSN's previous three COVID-19 surveys showed that this was already an important concern in 2020 and 2021, but the most prominent theme in the results of those surveys was concern about access to healthcare. Now, in 2022, access to care, although still a worry for many, is largely secondary to fear of the virus itself.

Respondents whose top concern is getting COVID-19



When asked about their greatest concern with respect to their cancer care after the lifting of COVID-19 restrictions, 21 per cent of patients and 38 per cent of caregivers mentioned fear of getting COVID-19 – a significantly higher percentage than in the previous survey.

Respondents who work with vulnerable people or in places where the virus spreads easily – such as schools and seniors’ residences – are especially concerned. They expressed frustration with the ubiquity of COVID-19 and the lack of protection for those most at risk. “*Students should still be masked,*” wrote a teacher with breast cancer in Ontario, arguing that this could have helped prevent students from getting sick: “*So much unnecessary COVID spread is happening.*”

“*I work with seniors and have lost eight people either to COVID directly or complications from having had COVID,*” said a uterine cancer patient in British Columbia. “*I know several people, both clients and friends, that are experiencing long-term problems from having COVID. People don’t use common sense and no longer seem to give common courtesy anymore.*”

Lifting of public health restrictions

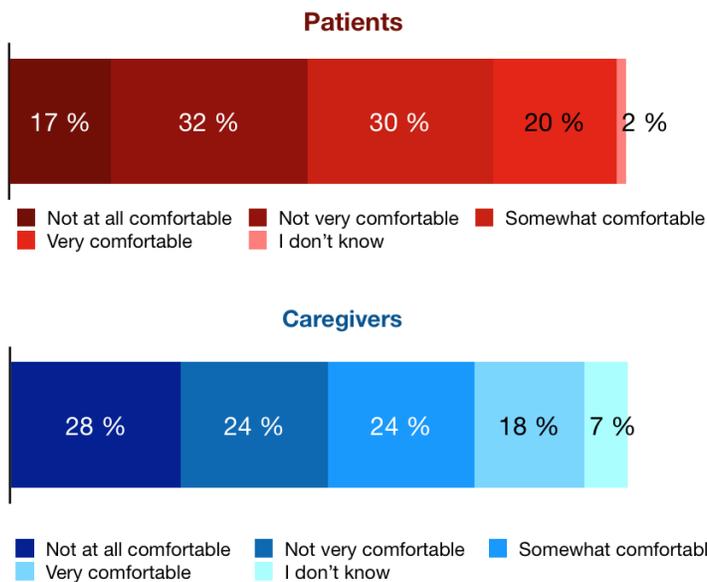
“The restrictions being lifted scares me. It makes me feel less protected. I have [been] home and alone even more now than when there were restrictions.”

— A stage 1 patient with multiple cancers in Alberta

For many cancer patients, public health measures designed to curb the spread of COVID-19 were what made them feel safe – whether visiting the hospital, going to the grocery store, or seeing relatives who might be more vulnerable to illness. Caregivers relied on public health restrictions to reduce the likelihood that they might transmit COVID-19 to the person they care for. The lifting of

these restrictions in most provinces that occurred in the first few months of 2022 has therefore put cancer patients at risk and caused them distress.

How do patients and caregivers feel about public health restrictions being lifted?



Half of the respondents (49 per cent of patients and 51 per cent of caregivers) were uncomfortable that their provincial government had lifted restrictions related to COVID-19. Caregivers were less at ease with this situation than patients: a higher proportion of caregivers said they were not at all comfortable with the lifting of restrictions (28 per cent) compared to patients (17 per cent), and a smaller percentage said they were comfortable with it (42 per cent, compared to 50 per cent of patients).

Those who felt ease with the lifting of restrictions, on the other hand, do not all have the same reasons for this attitude. When asked why, about a third of patients (33 per cent) and 28 per cent of caregivers who felt this way said that they were tired of the restrictions, that it is time to get back to normal, or something similar. Twenty per cent of patients who felt comfortable, though, had entirely different reasons for feeling comfortable, such as the Nova Scotia breast cancer patient who wrote: “*I feel wearing my mask, not being in crowded spaces, hand washing, and sanitizer will keep me safe.*” These respondents believed that COVID-19 still posed a serious risk, but that they could still protect themselves adequately by wearing a mask, avoiding crowds, etc. Only seven per cent of caregivers who felt comfortable gave reasons like these.

It is worth noting that the specific restrictions in place have varied a great deal across different jurisdictions and have changed over time. Although some respondents said, for example, “*restrictions were lifted too soon,*” speaking about restrictions in general, others had different opinions on different specific public health measures. A leukemia patient in Alberta, for example, found it worrying “*that people are not masking or taking any precautions when out in public, especially large events,*” but was unhappy with the restrictions in other ways. “*I have family members in care that I couldn't see*

and now they don't remember me," the patient wrote. *"This is very upsetting and stressful."* This is one reason that opinions on restrictions in general are quite divided in comparison to specific measures such as mask mandates.

Caregivers

Caregivers expressed greater anxiety about COVID-19 and more concern about loosened restrictions than patients. Comparatively fewer caregivers said they were comfortable with the lifting of public health restrictions, and significantly more named fear of getting COVID-19 as their top concern.

In CCSN's three previous COVID-19 surveys, caregivers have always been the subgroup for whom the impact of the pandemic has been the worst, in terms of access to care as well as concerns and anxieties. In this fourth survey, it is no different. Caregivers' worries have changed somewhat – delays in treatment are less of a concern, though not absent, and the prevalence of COVID-19 is a greater source of anxiety. The toll that the pandemic has taken on cancer caregivers remains, however.

They have also more often expressed concerns about how the behaviour of people around them affects the risk for themselves and – especially – for those they care for. *"The selfishness of the healthy is so frustrating. There's no care of the general public – or the government – for the vulnerable,"* said a caregiver for a bladder cancer and prostate cancer patient in British Columbia.

Frustration with people out in public who act in a way that caregivers perceive as inconsiderate of the risks faced by vulnerable people – not wearing masks, for example – was a recurring theme among caregivers. This frustration is often driven by caregivers' fear of passing the virus on to the person they care for – a risk that they feel they just cannot afford to take. *"I keep my mask tight on my face and avoid ANY indoor activity that would see me taking my mask off,"* continued the British Columbia caregiver. *"I live in fear every day that I will catch COVID and be asymptomatic – which would lead to loved ones DYING!"*

Caregivers are more likely to be caring for vulnerable people in the first place. Forty-one per cent of caregivers were caring for an immunocompromised patient (compared to 26 per cent of patients). Caregivers' loved ones are also more likely to be at a later cancer stage: 21 per cent of caregivers were caring for a Stage 4 patient, while nine per cent of patients were at Stage 4.

Expressing similar grievances, a caregiver for a Stage 4 esophageal cancer patient in British Columbia said: *"Immunocompromised people have all their freedom taken. The lengths to which healthy people do not care about anybody but themselves is deeply upsetting. That is why we have laws and mandates. ... You cannot withstand COVID in an immune compromised condition."* The lifting of the same public health measures, though felt by some – including some cancer patients – as liberating, was experienced by caregivers for immunocompromised patients as just the opposite.

Masks

Masks are seen by an overwhelming majority of patients and caregivers as an easy and effective means of preventing the spread of COVID-19. More than four in five respondents said they planned to continue wearing a mask even when it was no longer required, and one in five said that they wanted to see more people wearing masks (whether mandated or voluntarily) to feel safe in a world with COVID-19. No other public health measure was mentioned so frequently or so favourably.

Many patients see wearing a mask primarily as a way of protecting themselves from the virus. Explaining why they chose to continue wearing a mask, a Quebec thyroid cancer patient said: *“Because I do not want to catch COVID ... [I am] highly likely to get sick if not wearing a mask.”* A prostate cancer patient in British Columbia gave a similar reason: *“As a senior, 75 years old, I will take every precaution to make myself safe.”*

Others, however, are acutely aware that masks can only do so much if only a few people wear them – especially given the high transmissibility of Omicron and its sub-variants. This is especially so for people who care for immunocompromised patients or who work in settings where the risk of transmission is already very high. *“My husband is immunosuppressed from a single lung transplant. Our concerns are that Omicron is so easily transmitted and most folks aren’t wearing masks,”* said a caregiver for a carcinoma patient in British Columbia.

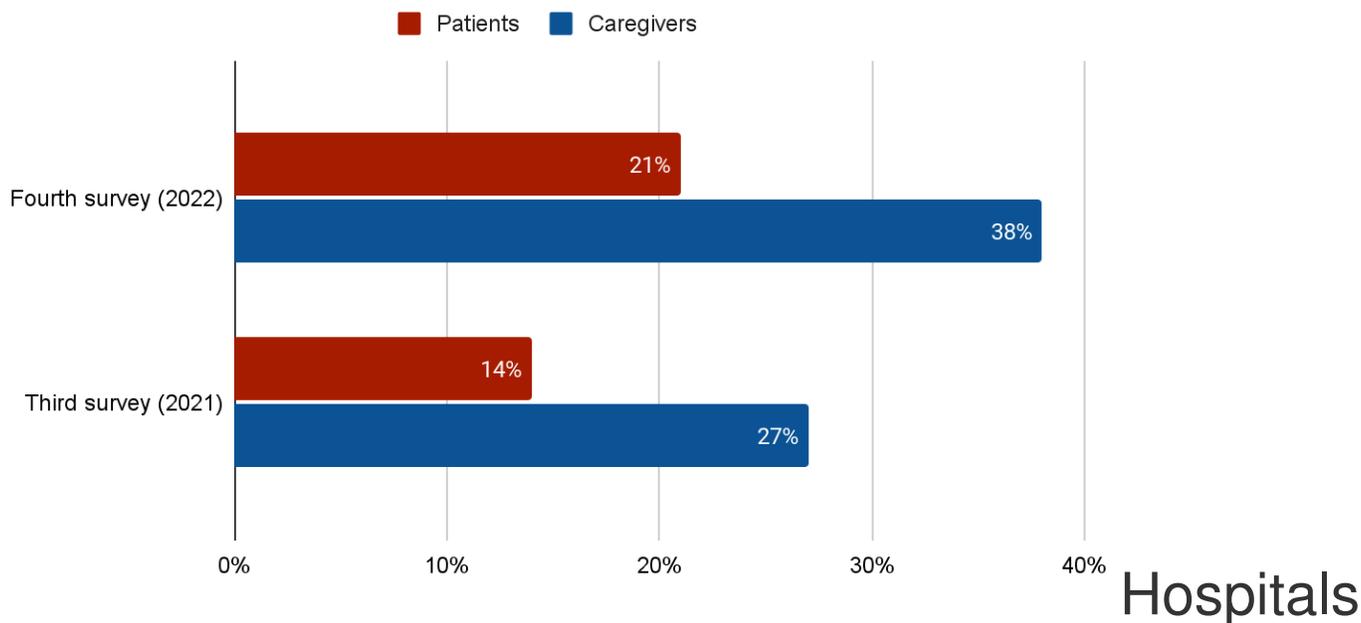
“I am an elementary school teacher where COVID is very prevalent amongst my school’s staff and students,” wrote a breast cancer patient in Ontario. *“I have elderly parents with health conditions, and I cannot visit them due to school exposure. I wish the mask mandate were still in place, because I have seen firsthand students, staff, friends, and loved ones getting sick like never before in this pandemic. I feel it is only a matter of time before I get it and could pass it to others – even though I wear a mask and have had my three shots.”*

Several respondents emphasized how little it costs to wear a mask for the benefit it provides. *“I believe wearing a mask to protect against the spread of the virus is much easier than being treated for COVID-19 along with the long-term side effects of having COVID-19,”* said a melanoma patient in Ontario. *“Masks provide quick, cheap, easy protection against the virus. It’s basically quite simple!”* Similarly, a bladder cancer patient in British Columbia opined that *“some restrictions which are relatively easy to comply with – like mask wearing – should be kept longer since they offer reasonable protection with little inconvenience.”*

Further testifying to the ease and wide tolerance of mask-wearing, a few patients who were opposed to other public health measures said that they were nonetheless content to wear masks. A prostate cancer patient in Ontario, who was also in favour of the lifting of public health restrictions, said: *“A mask is a very minor inconvenience, and it has been proven to help stop transmission. I will depend on the setting/circumstances. I will not wear it all the time when out.”* Similarly, a testicular cancer patient in Alberta, who was also glad to see the restrictions cease, expressed willingness to nonetheless continue wearing masks for the sake of others: *“I am not sure masks are effective. I don’t mind wearing them as a rule, but as the rule cedes, I will monitor people I am with as a guide to*

respect their risk / fear.”

Respondents whose top concern is getting COVID-19



“People still wearing masks and hand sanitizers and social distancing in the hospitals [should] continue after restrictions have [been] lifted.”

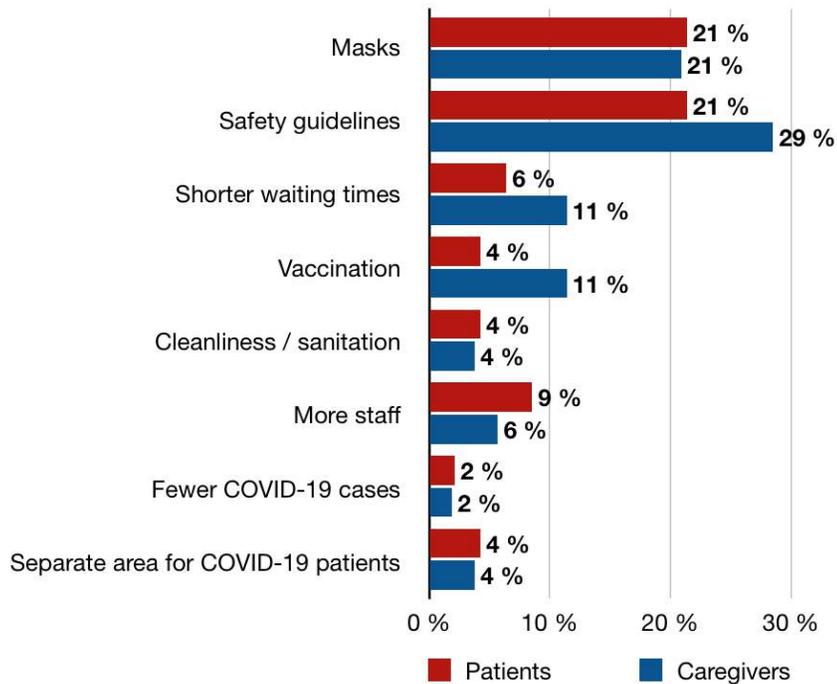
— A Stage 3 breast cancer patient in Ontario

About half of all respondents said that they did not currently feel comfortable visiting a hospital for cancer care. When asked what would make them feel comfortable, virtually all asked for more protections against COVID-19, especially:

- Strict COVID-19 safety protocols.
- Masks (either mandatory masks or more people wearing them voluntarily).
- Knowing that patients and staff were vaccinated against COVID-19.

In other words, what many cancer patients and caregivers want is for hospitals to continue implementing the same protective measures that had been in place in healthcare settings and many other places earlier in the pandemic. One patient simply wrote, for example, that they would prefer *“extending existing protocols for at least another year.”*

What would make patients and caregivers comfortable visiting a hospital for cancer care



Respondents were asked separately about whether they would feel comfortable visiting a hospital for reasons other than cancer care. In this case, significantly fewer patients (36 per cent) said they would feel comfortable, compared to 42 per cent of caregivers.

For respondents who felt comfortable visiting a hospital for cancer care but not for other reasons, masks were by far the most oft-mentioned measure to make them feel comfortable. A few patients mentioned wait times or that they felt no need to go to the hospital because they could see their family doctor.

It is striking to compare these results with the results of CCSN’s previous three surveys on COVID-19 and cancer. In those surveys, delays in getting treatment were a much larger problem; although there were respondents who chose not to go to the hospital for fear of getting COVID-19, these were a minority. The situation has clearly changed: cancer patients and caregivers are now expressing much less concern about wait times for treatment and much more concern about the risk of getting COVID-19 at the hospital, especially in the emergency room.

Although patients who are concerned about this are not necessarily choosing not to go to the hospital, the upshot is the same: cancer patients need to know that they are protected from COVID-19 to a reasonable extent in healthcare settings, and the healthcare system needs to be adequately equipped so that it can put these protections in place.

Access to care

The impact of the pandemic on cancer patients has changed since 2020. In the early months of the pandemic, cancer screenings in many places were suspended and many procedures and appointments for cancer care were postponed; the effect of these circumstances on cancer patients, caregivers, and pre-diagnosis patients was the focus of CCSN's first three surveys. Now, in 2022, concerns about access to care come in second to fears related to COVID-19 itself and frustrations with current public health approaches.

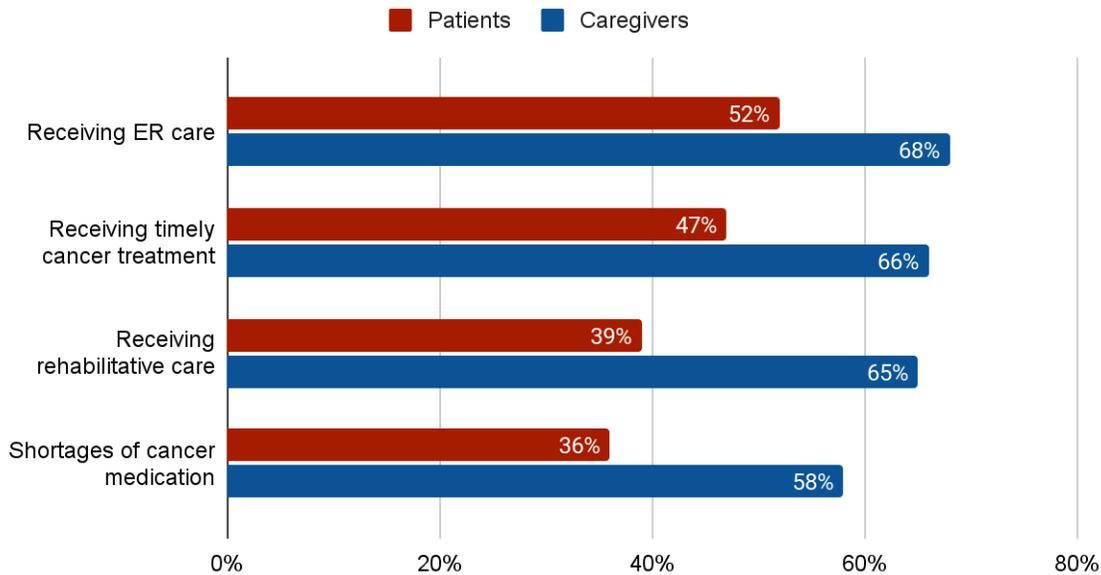
That said, when respondents were asked specifically about issues with accessing healthcare, the answers made it clear that these issues were still weighing on their minds. Two in three caregivers said they were concerned about whether their loved one could be cared for in an emergency room, and almost as many – 66 per cent – were concerned about whether the person they cared for would be able to receive timely cancer treatment. These concerns were also held by over 50 per cent of patients. These results represent significant increases compared to CCSN's previous survey in summer 2021. It also shows a reversal of a downward trend in anxieties about cancer care exhibited in CCSN's first three COVID-19 surveys.

"I am waiting for reconstruction surgeries, have been waiting for over 6 months, but am concerned that with the easing of restrictions, hospital rates will rise, and surgeries will continue to be delayed. I am not concerned about the actual virus impacting me," said an oral cancer patient in British Columbia. The lifting of COVID-19 public health restrictions was a common reason for concerns about access to care; in the same vein, an Ontario stage 4 prostate cancer patient wrote: *"With lifting of COVID restrictions, hospitalizations may increase again and make hospital care more restrictive."*

Concerns about access to care are now driven by different reasons. At this point in the pandemic, patients and caregivers are not typically worried about the kind of general delays that occurred earlier in the pandemic as part of public health responses when healthcare systems were trying to preserve hospital capacity and shift towards virtual care. Rather, they are mainly concerned that the healthcare system will be overwhelmed by new waves of COVID-19 and have less capacity for cancer care.

Patients in remission were not necessarily less concerned about access to care than those in active treatment. A Quebec thyroid cancer patient in remission said that their greatest concern was that *"we enter into such a serious deadly wave of COVID again and hospital wait times for non-emergency care will be put on the back burner, leaving patients struggling for health care."*

Concerns related to access to cancer care



Although difficulty accessing care is no longer the overriding concern for most patients and caregivers, it is still a tangible worry for many. The inherent uncertainty that accompanies a cancer diagnosis, combined with the ever-changing state of the pandemic and the strained healthcare system, together mean that cancer patients and caregivers have enough reasons to be anxious.

Conclusion

The change and uncertainty that has marked the pandemic from the beginning is not about to end. The SARS-CoV-2 virus will mutate, new vaccines and treatments will be developed, and public health policies will change. Cancer patients' need for protection from the virus and timely access to cancer care, however, remains the same. CCSN's fourth survey on the impact of the pandemic on cancer patients and caregivers in Canada shows that patients and caregivers fear that these needs are not being met.

Patients and caregivers differ in how much risk they accept and how far they go to protect themselves from COVID-19. They broadly agree, however, that the pandemic is not over; that cancer patients are especially vulnerable to COVID-19 and to disruptions to access to healthcare; and that public health tools such as masks and vaccines are still needed to keep cancer patients safe.

As much as cancer patients and caregivers do to protect themselves, the risks they face are largely outside of their control. They depend on others around them to reduce transmission of the virus by wearing masks and getting vaccinated; on hospitals and cancer centres to keep them safe while undergoing treatment; and on elected officials and public health authorities to give clear guidance and make sound decisions.

The Canadian Cancer Survivor Network calls on governments in Canada to preserve cancer patients' safety and access to essential cancer care in the face of not only the current pandemic, but future pandemics, natural disasters, and other crises.