
***SURVEY SUMMARY REPORT
“IMPACT OF COVID-19 PANDEMIC MEASURES
ON CANCER PATIENTS IN QUEBEC”***

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“We feel abandoned by the system”**Introduction**

The Quebec Cancer Coalition was created in 2001 to give a strong voice to people affected by cancer. It is a group of more than 60 non-profit organizations representing all cancer types and all regions of Quebec, which aims to improve the health care system in Quebec for the good of those affected by cancer. In particular, it defends the rights and interests of patients, survivors and caregivers. For nearly 20 years, its members have shared their vision for a healthier Quebec, centred on patients, survivors and caregivers.

This survey was designed following consultations with several members of the Quebec Cancer Coalition. The Coalition received a large number of communications from concerned patients, about the impact of the measures taken by the government to better manage the COVID-19 pandemic. The survey was conducted by the Quebec Cancer Coalition in collaboration with its members. The Coalition also validated certain concerns with health professionals in the field. By reading the various directives from the government, the *Ministère de la Santé et des services sociaux* and the oncology subcommittee, it was clear that measures were being put in place to be proactive and anticipate the health system's ability to meet the needs of the population. However, it was not clear whether the guidelines were being applied systematically, or what the direct impact on patients was.

In 2020, it was expected that 56,800 Quebecers would be diagnosed with cancer, representing 156 new cases per day, and that 22,400 people would die from it (61 deaths per day).¹ That we must not focus on a pandemic to the detriment of a health problem that is as important.

Under normal circumstances in oncology, changes and wait times are already causing anxiety among patients and their loved ones. Therefore, in the context of this exceptional situation, we felt it was essential to set up a survey to identify the concrete impacts of these measures, to identify the realities experienced by patients in the field, and to propose recommendations.

The survey was completed by patients in acute care or in follow-up (or their loved ones, if they could not), from April 3 to April 11, 2020. It was shared through the Coalition's and its member's social networks (Facebook, Twitter, LinkedIn), and through its members' mailing lists and e-newsletters. 592 people responded to the survey. As part of the survey, 10 questions (see appendix) were asked. For each of these questions, it was possible for respondents to share their concerns in writing.

¹ <https://fqc.qc.ca/en/information/the-cancer/statistics>

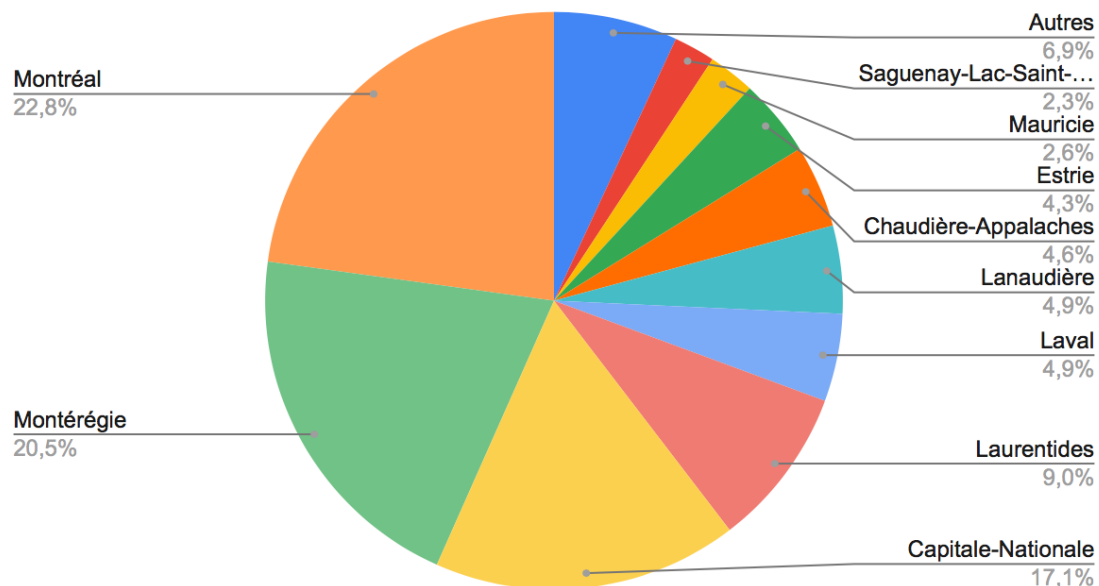
A- Description of the surveyed population

To begin, we present the characteristics of the 592 respondents.

1. Geographical origins

Of the 592 participants, 58% of them answered this question, i.e. 346 people. With the exception of the Nord-du-Québec administrative region, all other Quebec regions were represented. On the basis of the data collected, the three regions with the highest population density also were the three most represented: Montreal (22.8%), Montérégie (20.5%) and National Capital (17.1%). The least represented are the “Other” category (6.9%), which includes Côte-Nord (0.6%), Abitibi-Témiscamingue (0.9%), Centre-du-Québec (1.2%), Gaspésie-Îles-de-la-Madeleine (1.2%), Outaouais (1.2%) and Bas-Saint-Laurent (2%) (see Figure 1).

Répartition des participants par région administrative



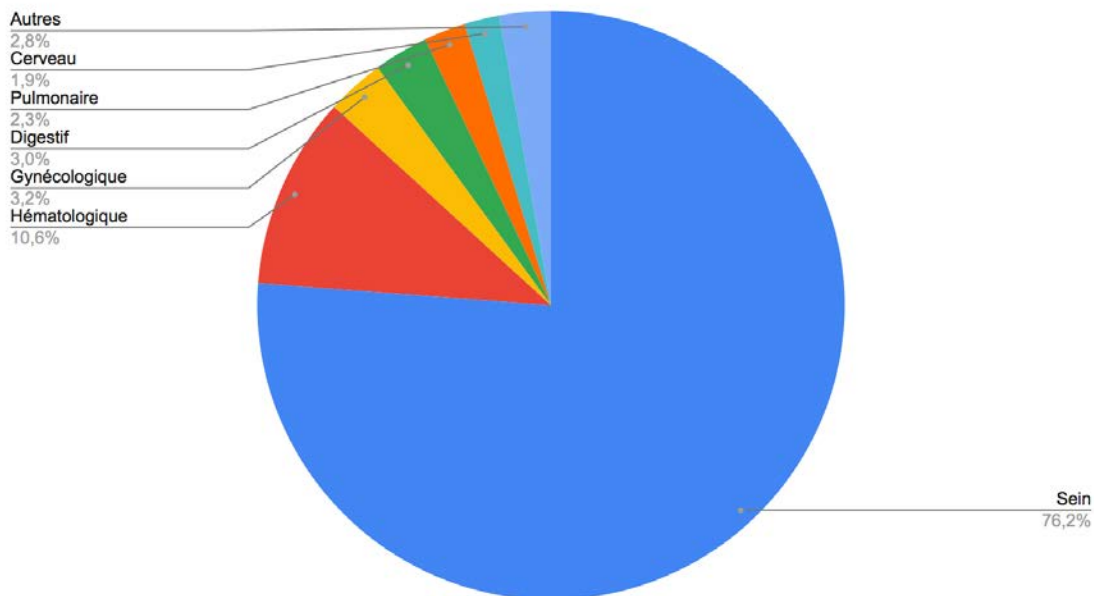
1. Cancer type

Of the 592 participants, 93% (553 people) specified the type of cancer for which they were being followed. The data were collected from respondents at different stages of their disease, some were expecting a screening appointment while others were in remission. Given that some participants had more than one type of cancer (n=14), each cancer was identified separately for a total of 567 diagnoses.

On the one hand, breast cancer, hematological cancers and gynecological cancers were the most represented types of cancer, describing, respectively, 76.2%, 10.6% and 3.2% of the responses collected. On the other hand, the types of cancer least represented among the participants are bone cancer (0.4%), thyroid cancer (0.5%), skin cancer (0.7%) and cancers of the urinary system (1.2%) grouped in the “Other” section (2.8%) (see Figure 2).

The over-representation of breast cancer may be caused by the very wide distribution of the survey by the [Quebec Breast Cancer Foundation](#) and the [Canadian Breast Cancer Network](#), by the fact that breast cancer is the most common cancer in Quebec among women, and by the fact that the postponement of surgeries because of COVID-19 disproportionately affects people with breast cancer.

Type de cancer des participants



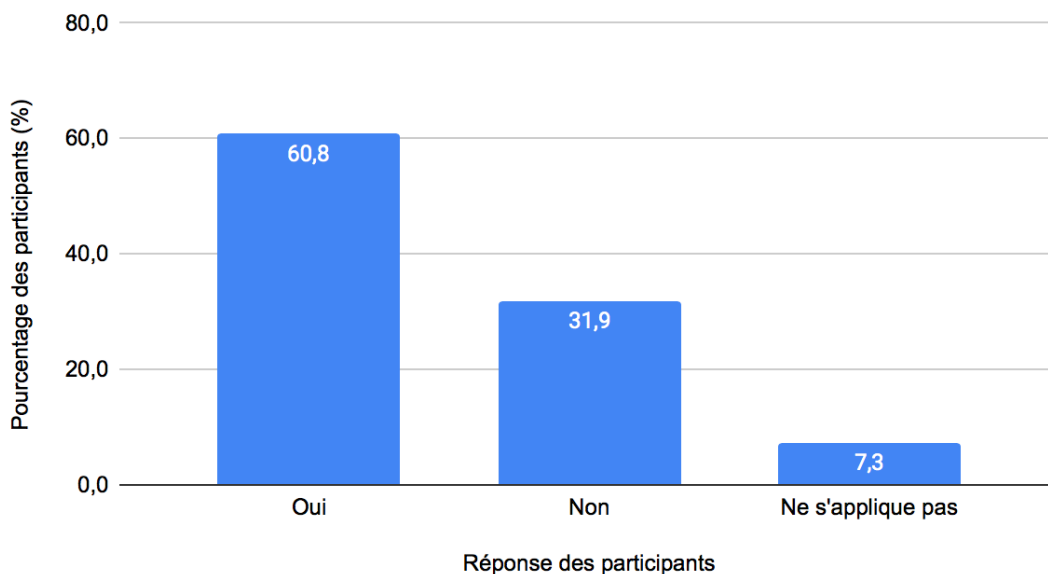
B- Description of situations experienced by respondents

In this section, we will first present the quantitative data and then present a synthesis of the comments that were written by respondents.

1. Quantitative data

1.1 Continuity of care and Services during the current pandemic

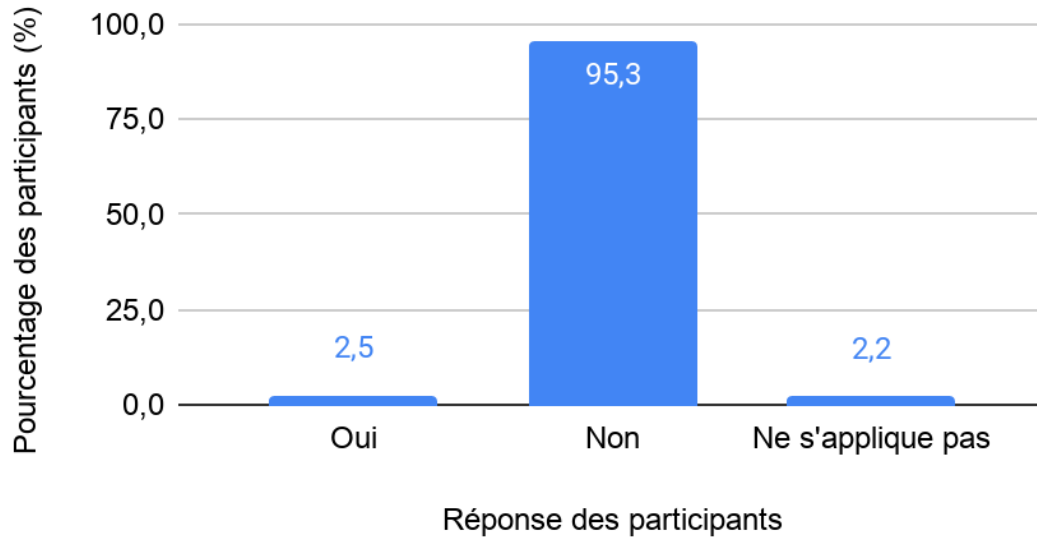
La situation actuelle a-t-elle affectée la continuité de vos soins?



Of the 592 participants, most felt that the current COVID-19 situation had affected the continuity of their care (60.8% of participants). Approximately 31.9% say that the measures put in place to deal with the current pandemic have not had an impact, and 7.3% consider that the question does not apply to their situation. The latter situation may concern patients who are in remission, for example.

1.2 COVID-19 tests

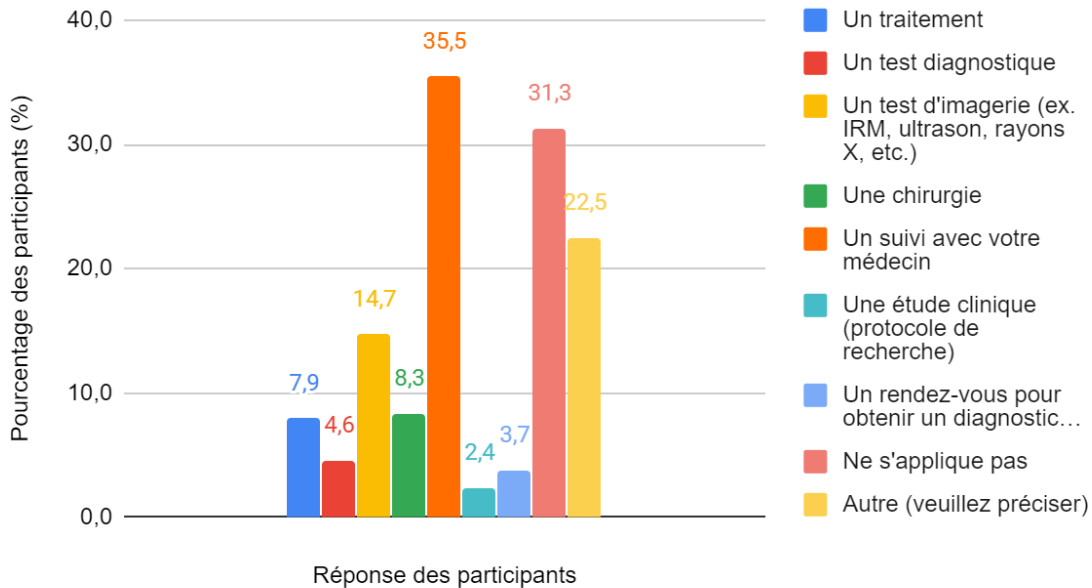
Avez-vous été testé pour la COVID-19 ?



Of the 592 participants, only 15 individuals (2.5%) were tested for COVID-19 because of a recent personal trip or a suspicious case in their entourage. The vast majority did not need to be tested, as these individuals are not symptomatic and are complying with the containment measures. These participants answered “No” (95.3%) or “Not applicable” (2.2%).

1.3 Postponement or cancellation of a scheduled appointment

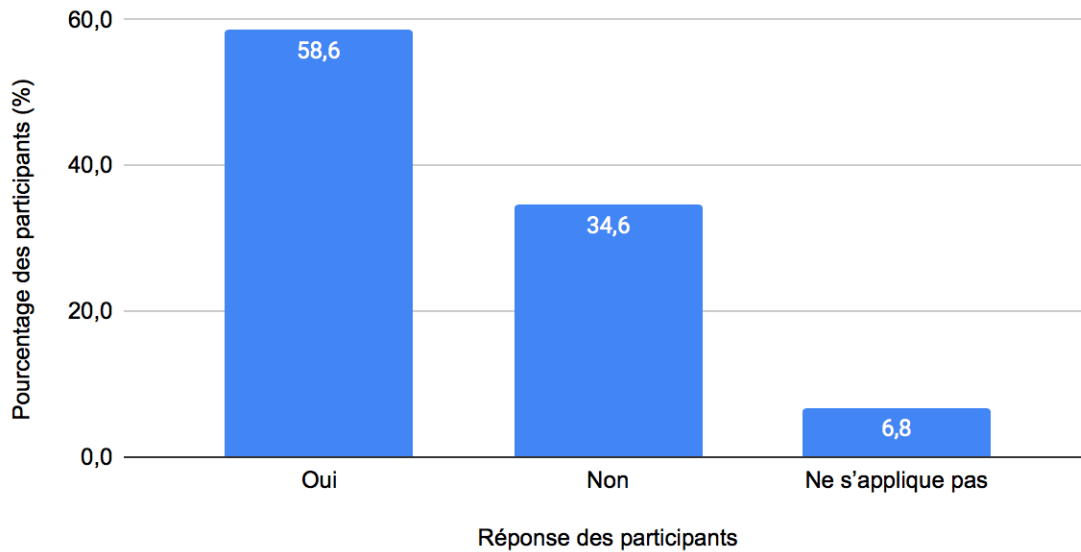
Types de rendez-vous reportés



Of the 592 participants, 31.3% consider that they are not affected by the postponement or cancellation of medical appointments. However, among those who do feel affected, i.e., nearly 68.7%, the types of appointments most concerned are follow-ups (35.5%), imaging tests (14.7%) and surgeries (8.3%). In addition, it should be noted that the “Other” category, which includes types of appointments not included in the response option proposed by the survey, has a large percentage, 22.5%.

1.4 Setting up a remote consultation with a professional during the month of March

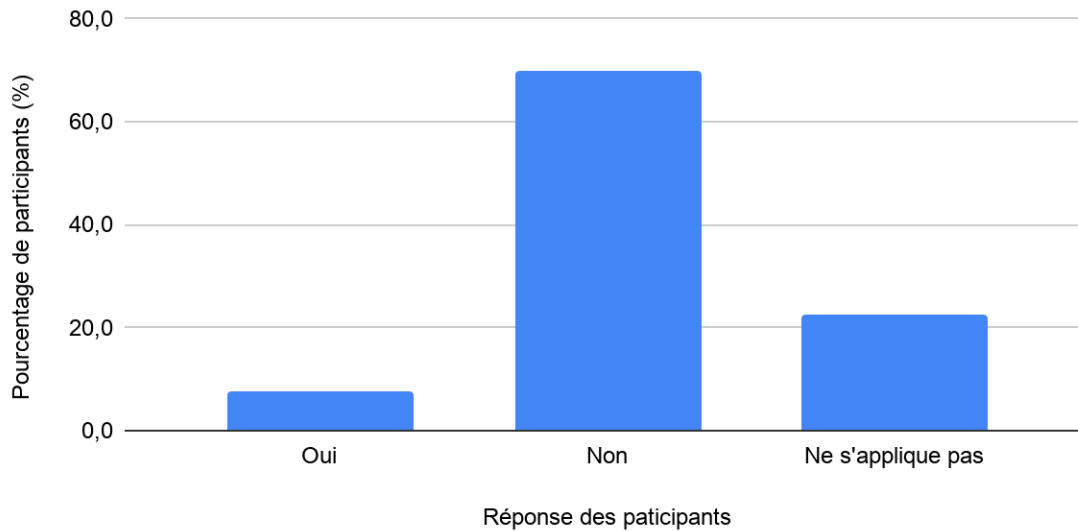
Personnes à qui la télémédecine a été proposée depuis le début du mois de mars



Of the 592 participants, more than half (58.6%) used or could be offered a remote consultation by telephone or videoconference. 34.6% responded that they had not used telemedicine, either because their follow-up absolutely requires tests or a physical examination or because they had not had the opportunity to do so. 6.8% of participants felt that this question did not apply to their situation, in particular because they did not have an appointment scheduled at that time.

1. 5 Difficulties accessing medication or treatments prescribed by a physician

L'accès aux médicaments ou traitements prescrits par votre oncologue a-t-il été difficile?



Of the 592 participants in the survey, a majority, 69.8%, did not experience difficulties in terms of access to medication and treatments prescribed by their oncologist. Some felt that this did not apply to their situation (22.5%) and 7.8% answered yes to the question.

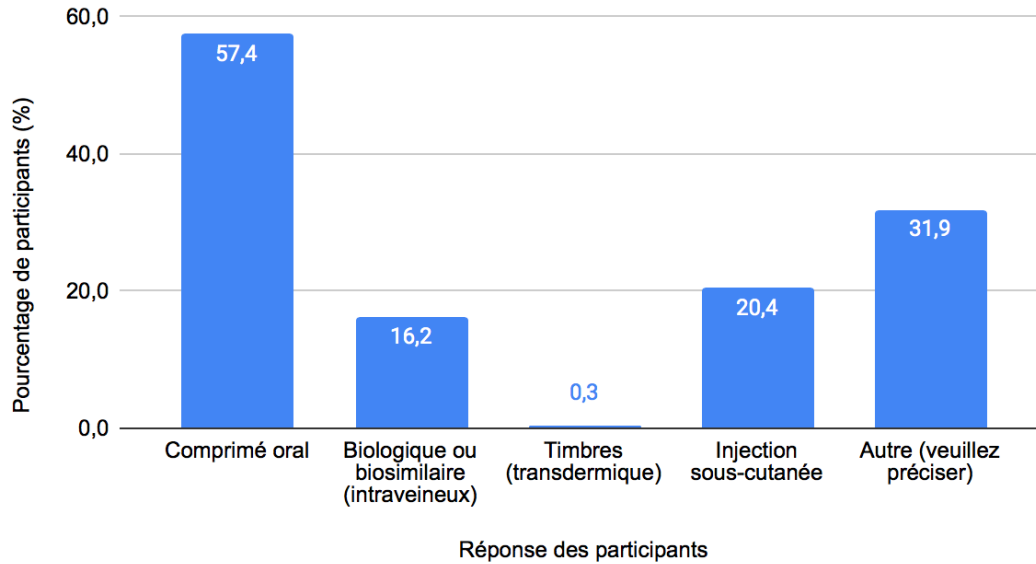
1.6 Medication shortages

A conditional question was asked in Question 5: **“If you answered YES to the previous question, what medication or treatment are you having difficulty obtaining?”**

Among the medications cited as being difficult to access are: Tamoxifen, Afinitor, Herceptin and Pertuzumab injections, Amiridex, and Pregabaline. It is important to note that this was only 35 mentions out of 592 respondents (5.9%), and that there do not appear to be serious drug shortage problems at this time.

1.7 Type of oncology drugs prescribed

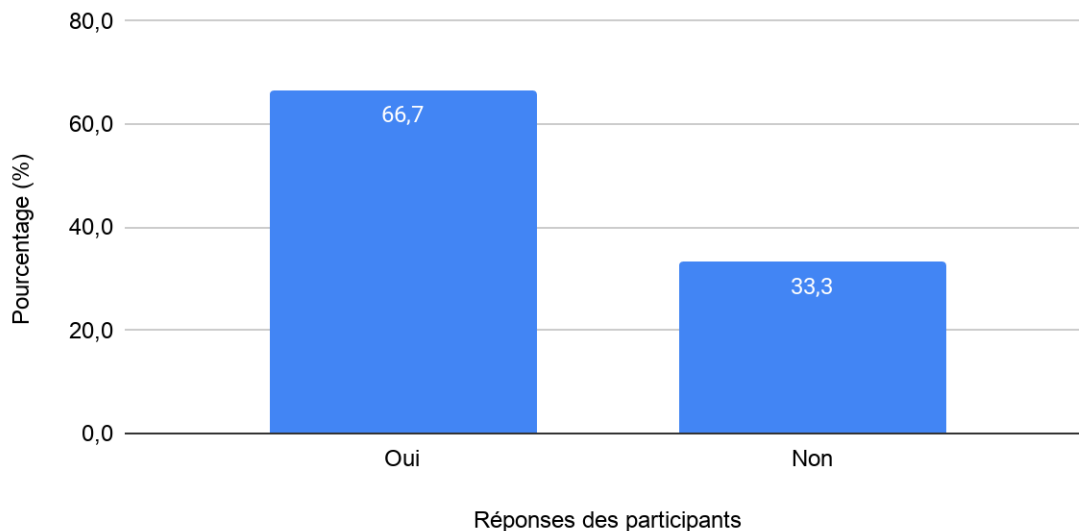
Types de médicaments oncologiques prescrits aux participants



Of the 592 participants, 57.4% were taking oral tablets for their cancer treatment and 31.9% responded that they were taking another type of oncology drugs other than those listed such as intramuscular or topical, among others.

1.8 Impact of the COVID-19 pandemic response measures on oncology patients

Pourcentage de répondants pour qui l'anxiété ou autre problème de santé mentale a augmenté ou s'est aggravé



Of the 592 participants, nearly two thirds are experiencing anxiety or worsening of existing mental health problems as a result of the pandemic situation, 66.7%, and 33.3% feel no change in this regard.

2. Qualitative data

The analysis of qualitative data identified several concerns from cancer patients with cancer in regards to the COVID-10 pandemic.

Thus, we will come back on the impact of the decisions made on access to the health care system, the impacts in terms of changes in treatment delivery, anxiety and fear, avoidance behaviour, how teleconsultations were experienced by patients, and the needs faced by some patients, as well as the situations that went well and even the gratitude some patients wished to express in via this questionnaire.

2.1 Accessibility and continuity of care.

A very large majority of patients shared their experience in terms of accessibility to the health care system, which leads to difficulties in the continuity of their care and services; they experienced numerous cancellations of appointments whether for screening, treatment, reconstruction or follow-ups.

In some places, all radiological or biological examinations have stopped (mammograms, scanners, etc.):

“No scanner examinations are possible at the CHUS during the pandemic.”

“I no longer have access to physical follow-ups such as blood tests and irrigation of my port-a-cath, as I have to stay away from the hospital.”

“My follow-up MRI appointment was rescheduled for an unknown date.”

“My Pet Scan will be delivered at a later date.”

“I am in remission from breast cancer and currently unable to book an appointment for a mammogram, which should be done every 6 months. I am unable to see my surgeon for my 6-month follow-up as well. This is worrisome.”

“That my follow-up MRI was cancelled by radiology without my oncologist's consent and that I don't have a date for the next exam. I'm having symptoms and it's difficult to manage.”

Some operations are either cancelled without a later date or postponed for several months:

“My mastectomy's been cancelled @#\$.”

“My surgery's been postponed for 5 months.”

“I'm waiting for a biopsy! This will determine whether or not it is cancer.”

“I was also scheduled to have the upper lobe of my tumour on my right lung removed on April 3rd, but as of April 10th I still have not heard from my surgeon.”

As for chemotherapy, intravenous immunotherapy or radiotherapy treatments, they have also stopped or been disrupted for some patients:

“An intravenous injection of antibodies has been cancelled today. However, the attending physician did not think it was necessary this morning to tell me about the next treatment, but only about the blood test in 6 weeks time and an appointment.”

“Chemo/surgery/chemo, all my tests (blood, taco, etc.) have been cancelled to confirm that everything is OK and that no new metastases have reappeared...”

“My immunotherapy treatment, which has kept me stable for two years, has been cancelled.”

“My preventive radiotherapy treatments were delayed for at least three weeks.”

“Last week, I spoke to my new oncologist and she told me that radiation treatments have been postponed to 4 1/2 months from now.”

On access to medication in the pharmacy, some patients experience difficulties:

“My original medication is no longer available in pharmacies, I have to take the generic and there is a significant increase in side effects.”

“They've been out of Tamoxifen for almost a year.”

“My oncology doctor prescribed hydroxychloroquine to relieve my severe arthritis in my hands. I couldn't renew my prescription. I am a make-up artist and I need this medication.”

“My pharmacy wouldn't give me medication for more than a month. I wanted to get some in advance.”

Les services en psychologie, la clinique de la douleur, la physiologie, etc. ont aussi été très ralentis voir arrêtés.

“I don't have any services from the pain clinic to manage my chronic pain caused by the cancer itself and its treatments. »

“My psychology follow-ups are fewer, despite my great need, especially in these times of pandemic. »

Patients have also chosen to change their behaviours themselves, because of their fear of catching COVID-19. This has also led to changes in their care pathways:

“I decided to delay the annual check-up mammogram and annual blood tests myself. I'll wait until the storm clears out. I'm in remission, operated in 2015.”

“I can't make my follow-up appointments, I'm too afraid to catch it.”

“My ventriculography exam has been delayed but I understand. I'd rather delay than take the risk of showing up at the hospital.”

“I'm going to cancel my appointment with my oncologist and reschedule it for a later date.”

2.2 Change in treatment delivery

Due to the reorganization of services and risks of infection, treatments have been modified for some patients:

“My treatment has been doubled in order to attend once a month instead of twice.”

“Yes, I received my last chemo treatment 2 weeks in advance. Instead of being a simple treatment, it was tripled to make sure I didn't go back to the hospital too often.”

“Yes, because my X-ray treatment was first cancelled and then went ahead as planned. Rather than having 25 treatments, I'll have 16 to cut down on hospital visits. Congratulations to all of you for making quick decisions.”

“Herceptin treatment every 4 weeks instead of every 3 weeks.”

“We paused two chemotherapy treatments because with the pandemic, it was too risky to go to the hospital while having no immunity.”

2.3 Increased anxiety, fear and isolation

There is a lot of anxiety in patients' responses. This anxiety or fear is expressed in several ways.

First of all, patients are already anxious in normal times, and the addition of the health crisis that makes it difficult to be treated only amplifies the situation:

“This pandemic is making me anxious all the time. Because now I' on my own while undergoing difficult treatment. Anxiety is tightening my chest, making it smaller and causing breathing difficulties, a symptom of Covid-19, which in turn causes anxiety.”

Patients fear that lack of treatment will worsen their condition and jeopardize their vital prognosis:

“I'm concerned because the cancer was grade 3. I hope it won't come back.”

“I'm afraid my surgery will be delayed and my cancer won't be removed in time.”

“I'm afraid I'll be forgotten. My cancer's not supposed to be invasive. But I'm afraid I'll have to wait a long time because there are other more serious cases waiting. I had received 5 calls confirming, cancelling and rescheduling surgery and finally the day before my surgery, I received a call from the surgeon to cancel the surgery. It was a roller-coaster ride.”

“I'm worried that the stage of the cancer is changing. I need to have the surgery that was planned so I can get better and go on with my life. Because I have some help at home during the confinement, it would be the ideal time for recovery vs. taking care of my 4-year-old daughter.”

“Anxiety is always present, the fear of wondering if (my) cancer will get worse. I wake up at night with my hand on my breast wondering if the surgery will be done soon.”

“I understand the urgency of the situation, but I feel abandoned as I am a patient with a fatal chronic disease...I fear that my treatments will be delayed, that I won't be able to do a quick resonance to check on the progress of the disease following a CT scan last February...and I'm certainly afraid of catching the virus, not surviving it or worse, that the hospitals will be overwhelmed and will have to

choose which patient to save...in which case, I would clearly lose. I've been followed every 3 months for 3 1/2 years. The fact that this rigorous follow-up, which is necessary for my survival, may not be available for some time, especially when as I am being followed for possible disease progression, causes me a l."

It also leads to a lot of isolation and questioning on being able to accompany their loved ones:

"I feel so isolated, I don't have access to any help. I started my treatment on March 17."

"I'm missing a lot of interaction with people who are going through the same thing I'm going through. I also lack individual treatment (e.g. reiki, massage, etc.)".

"I don't know if I'll be able to accompany my spouse to his appointment after the radiotherapy and chemotherapy treatment in early May, we're keeping our fingers crossed."

"My biggest concern is that I can't last until the end of this isolation and that means that I won't be able to say goodbye to my family and friends in person, and that I would die alone, which is terrifying for me, and so sad for my partner. I also won't have the funeral party that I imagined."

Patients are very afraid of catching the Coronavirus:

"My biggest concern is catching COVID."

"I'm in chemo and I'm more anxious to get the virus because of some people who don't follow the instructions."

"I'm afraid I'll catch the virus and not get out."

"My biggest concern is that I'm going to get sick with the virus. I am taking every precaution that is indicated. Yet fear of the unknown causes anxiety."

"Being infected by asymptomatic essential workers."

"Anxiety to get to the hospital to receive my Herceptin treatment."

" I'm afraid I'll catch it and not get through it because I'm stage 4. "

"I'm always afraid of catching it, because our immune system is probably not at its full potential."

And not to have access to their treatment :

“I'm very worried that of having trouble finding my hormone therapy. In addition, I have to change my hormone therapy protocol in June and I will have to go to a CLSC for injections and blood tests every month from then on.”

“I'm also afraid that they're going to run out of medicine or cancel my life-saving treatments.”

Finally, the temporary closure of research protocols and clinical studies is worrying many patients and their families. For patients in third-line care or with metastatic cancer, clinical research offers hope and often the best treatment option.

“I'm not getting the best course of treatment because the protocol at the CHUM is closed, and I'm having difficulty accessing other clinical studies that are also closed.”

2.3 Frustrations towards the health system

The heavy emphasis on COVID-19 has also led to a great deal of frustration for some patients:

“I think it's unfair that all the attention is being given to COVID 19 patients when the people who need to be treated for cancer are being left out in the cold.”

“The priority of the system appears to be to maintain capacity to accept large numbers of patients with COVID-19. While this priority is justifiable, it is unfortunate that medical interventions expected by people suffering from other diseases are delayed. This is not the case for me, as my treatment was completed 18 months ago.”

“My doctor has received the results of a CT scan and won't call me with the results. Everything leads me to believe that COVID-19 is taking over. I had to have surgery.”

“But I don't think it's the fault of the nurses or the oncologists who are clearly doing their best. That said, there is a real risk that we won't be seen, tested or operated on in time, thus increasing the risk of mortality from metastasis, as well as giving the tumour time to become even more malignant.”

“My surgery has been postponed indefinitely. It's a fiasco. According to the information I have, operations have resumed, but not according to my surgeon. The beds are available, the system is well prepared and there is no COVID-19 virus in the clinic. Our surgeons are not operating. So what's the story? There wasn't any problem in Quebec as of April 1, my initial date.”

As well as a lack of understanding of the little interest of decision makers for patients suffering from other pathologies:

“My biggest concern is the lack of awareness in policy makers' speeches about the fragile health of people with chronic/immunosuppressed diseases. I think it would be relevant when it comes to the 70+ age group to include this category to raise awareness. I fear that with deconfinement, I will be left out of the protective measures given my young age, despite my immunosuppression.”

2.4 Telemedicine

Despite major changes in the reorganization of care, some patients have been offered consultations by telephone or teleconference, not only from physicians, but also from psychologists and physiotherapists :

“Appointments with my surgical oncologist are by phone.”

“My doctor cancelled my appointment and replaced it with a phone call.”

“The next appointment on May 5 with my oncologist will be by phone.”

I got a call from my oncologist on the phone for a follow-up.”

“I was in the middle of changing my hormone therapy medication (hormone-dependent breast cancer) and my follow-up appointments were not kept. Luckily, my oncologist is communicating with me by text/email so we are in the process of resolving the situation.”

Some are satisfied and even see benefits...

“My neurosurgery appointment was over the phone. Not so bad.”

“My surgeon made a very satisfactory follow-up call.”

“I also take this opportunity to point out that I particularly appreciate the telephone appointments that save me time and travel, and that are just as effective as a face-to-face meeting for the type of follow-up that my condition requires. I believe that if the pandemic makes telemedicine more accessible, it would be a great step forward for our health care system.”

“I thought it was safe to do the consultation over the phone.”

“I got two phone calls from Maisonneuve Hospital. The secretaries and nurses are doing an excellent job and follow-up.”

... others see limitations:

“Yes, it's done over the phone, but there is no physical exam, which is very important.”

“It's harder meeting the doctor on the phone than a face-to-face meeting, but I get it.”

“Yes, I had a phone appointment, but it didn't allow me to have my blood test.”

“It's scary not to have more physical contact... when you have certain fears.”

“It's not as effective as a one-on-one meeting, but I understand these circumstances.”

2.5 Positive follow-up or no impact on follow-up

In the responses received, some patients indicated that the pandemic had not had an impact on their treatment. Their numbers are far fewer than those who reported difficulties. Here is how they highlighted how professionals were able to maintain activities:

“I had a biopsy report, the surgeon saw me two days later and I will be operated on next week.”

“I'm having my first right breast surgery on Thursday, April 16th.”

“For the time being, my chemo treatments are continuing.”

“Chemo was continued and thanks to all the staff for the good care.”

For some patients who are in remission and did not have an immediate appointment, they see no change, and for those who are expected to be in remission in several months, they hope that this can be done in the best possible conditions.

2.6 Needs not met beyond health problems

For some patients the situation is dramatic financially. They do not have enough money to feed themselves, buy essential goods and raise their children. This is due to their situation where, having been sick, they have not accumulated enough hours to benefit from certain programs:

“Food and hygiene products have become more expensive, while I am receiving a disability benefit of \$540 per month, an amount that does not cover my needs.

‘Financially, it's difficult.’

‘I can't sell my house because of the shutdown.’

'I'm having trouble making ends meet.'

'I NEED FINANCIAL HELP'

'Because I have not been able to work in 2019 due to salary and operations, I am not eligible for any government financial assistance programs related to COVID-19 because I did not earn a minimum of \$5,000.00 last year or in the last 12 months.'

'I started working part time again at the end of February 2020 and 3 weeks after we had to be confined (so lost my job), I didn't have time to earn enough money to get into the current programs.'

I phoned the federal and provincial MP, wrote to the primer ministers, Mr. Trudeau and Mr. Legault, and made a request to the Red Cross, and the MPs and the Red Cross replied, 'You are not part of the program requirements. SO \$0.00 I NO LONGER HAVE ENOUGH TO LIVE ON.'

'I'm self-employed, I'm single and raising a child alone and my family lives far away and I haven't worked for 3 weeks and my office is commercial with a fixed fee that I can't pay. And I can't use integrative help and I have an ineffective follow-up because of COVID. (but the nurses and doctors are doing their best).'

In such a difficult time for patients, the closure of all centres to promote well-being is experienced in a very difficult way:

'My greatest need, especially during this period, is well-being (nutrition, mental health, and physical health). The very few cancer wellness centres in Quebec (which operate entirely thanks to donations) are naturally closed. I think that the cancer wellness centres need support to be able to sustain us during this period when their services are most needed. '

'The Quebec Breast Cancer Foundation suddenly decided to cancel its funding for the adapted yoga activities it was offering. The teachers had taken steps to offer quality sessions at a distance (Zoom, etc.). It was very disappointing since this activity is one of the few that breaks the isolation.'

Another need that has also emerged is the lack of information that is passed on to patients in relation to the postponing appointments and treatments and changes in the delivery of care. Patients need to have better explanation of the impact this can have on them:

'My greatest need is transparency from my health care team - to know the real impact of the pandemic measures on the decisions I make and the continuation of my care plan. Being well-informed limits anxiety and interpretation (including comments about support groups where women feared their stage 1 cancers

would progress to stage 4 within weeks if treatment did not take place on the scheduled day).’

‘I need to be reassured that my treatments will take place after surgery.’

‘I've been a researcher in life sciences and medicine for 26 years. The health care system doesn't even ask me who I am! They assume I'm ignorant and don't even tell me what they're doing. In fact, I even question their knowledge - when I had my biopsy, I asked my radiologist about the pathology of the samples she took from me. She gave me such a stupid and insulting answer that I could only question her competence. I am not a medical specialist, but the lack of interest in me and my knowledge base is shocking. I would never do that with my clientele! ’

2.7 Solutions found

Solutions that bring comfort to patients include support groups:

‘I've been doing very well since I attended all the support groups before the services closed. Participating in daily exercise programs also helps me.’

2.8 Acknowledgements

And finally, here are two excerpts from people who wish to thank the Prime Minister and their health care team:

‘I commend the Prime Minister and his colleagues for their handling of this crisis.’

‘Very good communication with my oncology team. Very collaborative care. No concerns to date.’

Conclusion and Recommendations

With 61% of respondents reported that their health care and services were modified as a result of the measures put in place to curb the pandemic, and with the qualitative data analysis showing a large number of comments on this subject, we conclude that a large majority of people affected by cancer currently feel "abandoned" by the health-care system.

RECOMMENDATIONS

1. **Raise public awareness that health conditions other than COVID-19 are also important and are being considered.** Although this is occasionally mentioned, the Ministry of Health and politicians could publicly review, on a more regular basis, the measures put in place to ensure that cancer care and services - as well as those for all other patients requiring urgent care (heart attack, stroke, etc.) or with chronic diseases (diabetes, chronic obstructive pulmonary disease, immunocompromised patients, etc.) - are maintained as much as possible in a safe setting.
2. **Continuing with this type of consultation** on a regular basis would be required in order to be able to monitor the experiences of patients living with cancer and to measure as accurately as possible the impact on their distress and psychological health.

Lack of information is a challenge at different levels. Patients need to be better informed and reassured, as well as being provided with relevant information about the consequences and impacts of the decisions that affect them.

RECOMMENDATIONS

3. **Encourage professionals to establish better communication** with patients - virtual or face-to-face - so that they can understand the impact of the situation on them and on the prognosis of their cancer. Professionals from the Ministry of Health and the Quebec Cancer Programme could offer communication guidelines to oncologists to help them explain in a simple manner the impacts of these changes and what medical alternatives are possible in the short, medium and long term (clear explanation of treatment changes: risks / results / procedures).
4. **Set up an INFO-ONCO-COVID line** to provide people affected by cancer with an information resource that can respond to various concerns and provide accurate information.

It is important to note that in other health systems, the impacts of the coronavirus crisis management plan have led to a significant increase in mortality with cases not related to COVID-19^{2,3}.

RECOMMENDATIONS

5. **Ideally, cancer-related death rates should be published** and the government should carry out **short- and medium-term monitoring of specific cancer-related mortality rates**. Up-to-date data from the Quebec Cancer Registry are still more than 10 years overdue.
6. **Plan a "post-COVID" recovery plan to monitor wait times** for all short-, medium- and long-term procedures in a transparent manner (surgery, chemo, immunotherapy, radiotherapy, brachytherapy, etc.) to get back on track and prevent the inevitable new cancer cases from clogging up the system and increasing mortality rates.
7. **Monitoring stock outs of certain drugs and assessing their impact** should also be taken into consideration. A risk management policy in relation to drug shortages could mitigate the impact on patients.

Some patients are in an extremely precarious financial situation simply because they do not meet the eligibility criteria for the current government programs in place. This situation is unacceptable.

RECOMMENDATIONS

8. **Ensuring a safety net for patients in serious financial difficulty** seems imperative to us.

Wellness activities are being sorely missed by patients and isolation is very difficult for patients and their loved ones.

RECOMMENDATIONS

9. **Establish virtual options to offer well-being services and support groups** - as offered by certain foundations, community organizations or patient associations - should be maintained and encouraged by promoting the creation of virtual exchange spaces.
10. **Promote the participation of family and friends in medical consultations through telemedicine** so that people affected by cancer can be accompanied, even if the person accompanying them is not in the same place.
11. **Maintain the connection between hospitalized patients and their loved ones** - whether virtually or limited face-to-face options, in order to avoid the perverse effects of isolation.

² <https://www.theguardian.com/world/2020/apr/08/alarm-sounded-over-rise-in-non-coronavirus-deaths-in-scotland>

³ <https://nymag.com/intelligencer/2020/04/coronavirus-is-only-part-of-the-excess-fatality-mystery.html>

12. **Allow the presence of at least one caregiver in end-of-life care** so that people can be accompanied while living their last moments.

The management of the COVID-19 crisis is having a significant impact on the levels of fear and anxiety experienced by patients, mainly related to the fear of contacting the virus and the fear of not being able to access the health care system in a timely manner. Considering that it can certainly be detrimental to delay surgery for more than two months, we feel it is important to consider alternative solutions.

SUGGESTIONS

13. **Reorganize services** by allowing facilities to accommodate patients requiring oncology treatment without putting them at risk of contracting the virus :
 - A. **Refer surgeries to dedicated facilities** not identified as receiving patients with COVID-19 in order to avoid placing oncology patients in settings where they are at risk of contracting the virus and to limit cancellations and postponements.
 - B. **Perform intravenous treatments outside of hospitals, for example, in infusion centres.** To avoid contact of immunocompromised patients with “hot zones” in institutions, consideration could be given, for example, to using infusion centres with excess capacity to perform intravenous treatments.
 - C. **Prioritize medications that can be administered at home** (when possible).
 - D. **Promote home care** through existing resources, such as: CLSCs, community pharmacies or organizations such as NOVA Montreal for palliative care. These are avenues to be explored in order to avoid exposure to the risk of contamination by COVID-19 (however, only if staff have the necessary protective equipment).
 - E. **Establish a mental health support program** providing access to psychologists specializing in cancer or serious illnesses, in addition to sharing useful resources for cancer patients.

We have also noted that clinical studies have been put on hold to allow a reallocation of staff in anticipation of a potential hospital overload. However, since this situation is well controlled by the measures put in place and has been averted, and has a real impact on the lives of affected patients, we feel that the risk to patients is greater than the benefit of reallocating resources.

RECOMMENDATION

14. **Re-establish research protocols as soon as possible**, especially for treatments of advanced or rare cancers for which there are no other promising treatments.

The qualitative analysis demonstrates that telemedicine consultations are greatly appreciated by patients.

RECOMMENDATIONS

15. **Maintain telemedicine and deploy** it as widely as possible, not only during the pandemic but also afterwards.

SUMMARY OF FINDINGS AND RECOMMENDATIONS

Summary of findings

- **592 people surveyed from all regions of Quebec, 76% of whom have breast cancer.**
- **60.8%** of respondents saw their care affected by the management of the health crisis due to COVID-19.
- The types of care most affected by delays or cancellations are: **medical appointments (35.5%) and radiological tests (22.5%)**.
- **58.6%** of people were able to benefit from follow-up by **teleconsultation**, which was most often appreciated even though for some patients it does not replace a physical examination.
- **66.7%** of respondents saw their **anxiety** or psychological health problem increase or worsen.
- The main causes of this anxiety are: **difficulty - or even impossibility - accessing treatments** (surgery, chemotherapy, immunotherapy and radiotherapy); **risk of jeopardizing their vital prognosis; fear of contracting COVID-19;** or the **increased isolation** that prevents them from benefiting from the assistance of their loved ones.
- Patients are asking that oncology professionals **explain the impact of treatment changes and appointment rescheduling on their health status to them**. This leads to a great deal of frustration from those affected, who feel that the system is abandoning them.
- Some people who do not meet the eligibility criteria for the financial aid programs currently offered find themselves in a **very precarious financial situation**, jeopardizing their ability to eat properly and have access to basic hygiene products.

Summary of recommendations

1. Raise public awareness that health conditions other than COVID-19 are also important and are being considered.
2. Conduct regular online surveys to assess the impact and level of psychological distress of people affected by cancer.
3. Encourage professionals to improve their communications with patients to reassure them of the impact of current changes to their care.
4. Set up an INFO-ONCO-COVID line.
5. Publish specific mortality rates related to cancer in the short, medium and long term.
6. Provide a "post-COVID" recovery plan to monitor wait times for all procedures in the short, medium and long term in a transparent manner.
7. Monitor stock outs of certain drugs and assess their impact.
8. 8. Ensure a safety net for patients in serious financial difficulty.
9. Establish virtual options to deliver wellness services.
10. Promote the participation of family and friends in consultations through telemedicine.
11. Maintain the connection between hospitalized patients and their loved ones.
12. Allow at least one family member to be involved in end-of-life care.
13. Reorganize services :
 - A. Refer surgery to dedicated, non-COVID19 establishments ;
 - B. Carry out intravenous treatment outside of hospitals, for example in infusion centres ;
 - C. Give preference to drugs that can be administered at home ;
 - D. Promote home care ;
 - E. Set up a psychological support programme.
14. Re-establish research protocols as soon as possible.
15. Maintain telemedicine and continue to deploy it.

ANNEX 1: THE QUESTIONNAIRE



Impact of COVID-19 pandemic measures on cancer patients in Quebec

SURVEY ON THE CONTINUITY OF CARE: COVID-19 & Oncology

The Quebec Cancer Coalition (Coalition Priorité Cancer au Québec) wishes to know the impacts and challenges caused by government measures to counter the COVID-19 pandemic on cancer patients.

By gathering your experience and testimony, we hope to identify some current problematic situations as well as to propose potential solutions to the Quebec Ministry of Health and Social Services.

Your participation will allow us to suggest improvements for all Quebecers, and for that, we sincerely thank you.

* 1. In your opinion, has the continuity of your care been affected (or will it be) by the measures for the COVID-19 pandemic?

- Yes
- No
- Not applicable

Comment

* 2. Have you been tested or are you scheduled to be tested for COVID-19?

- Yes
- No
- Not applicable

Comment

* 3. Have you had any cancellations or postponements for the following situations:

- | | |
|--|---|
| <input type="checkbox"/> Treatments | <input type="checkbox"/> Medical follow-up with doctor |
| <input type="checkbox"/> Diagnostic Testing | <input type="checkbox"/> Clinical study or research protocol |
| <input type="checkbox"/> Medical Imaging (ex. MRI, ultrasound, X-Rays, etc.) | <input type="checkbox"/> Appointment to get diagnosis and develop care plan |
| <input type="checkbox"/> Surgery | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> Autre (veuillez préciser) | |

* 4. Have you received, or been offered, consultations with health professionals by telephone or videoconference since March?

- Yes
 No
 Not applicable

Comment

* 5. Have you had difficulty accessing the medications or treatments prescribed by your oncologist?

- Yes
 No
 Not applicable

Comment

6. If you answered YES to the previous question, which drug(s) or treatment(s) are you having trouble obtaining?

* 7. What type of oncology drugs do you take for your treatments?

- Pills (oral)
 Biologic or biosimilar (intravenous)
 Patches (Transdermic)
 Sub-cutaneous injection
 Autre (veuillez préciser)

* 8. Is this pandemic causing you more anxiety than usual, or or aggravating your existing mental health issues?

Yes

No

Comment

9. Have you experienced other problems that have not been identified in connection with the measures for the COVID-19 pandemic that you wish to communicate to us? What is your greatest concern / need in the current context?

10. What type of cancer are you being tested or treated for?

11. Would you like to share your contact details with us to stay in touch (ex. follow-ups, newsletter, etc.)?

Nom	<input type="text"/>
Ville/Localité	<input type="text"/>
Region	<input type="text"/>
Postal Code	<input type="text"/>
Email	<input type="text"/>
Telephone number	<input type="text"/>

ANNEX 2

MEMBERS OF THE QUEBEC CANCER COALITION

Association du cancer de l'est du Québec (ACEQ)	Groupe espérance et cancer
Association pulmonaire du Québec (APQ)	Groupe McPeak-Sirois
Association québécoise des ergothérapeutes en pratique privée (AQEPP)	Groupe des aidants du sud-ouest
Association québécoise des registraires en oncologie (AQRO)	Huddol
Association québécoise du lymphœdème (AQL)	Innovation Exactis
Association québécoise de soins palliatifs	Institut de recherche en immunologie et en cancérologie (IRIC)
BioCanRx	La Fondation canadienne des tumeurs cérébrales
C3i	La Fondation sauve ta peau
Canadian Cancer Survivor Network (CCSN)	L'espoir, c'est la vie
Canadian Virtual Hospice	Life-Saving Therapies Network (LSTN)
Cancer colorectal Canada (CCC)	La Rose des vents de l'Estrie
Cancer de la thyroïde Canada (CTC)	Lung Cancer Canada
Cancer de la Vessie Canada	Lymphome Canada
Cancer de l'ovaire Canada (COC)	Maison St-Raphaël : Maison de soins palliatifs et centre de jour
Cancer du rein Canada	Myélome Canada
Cancer Saguenay	NOVA Montréal

Cancer Testiculaire Canada	Oncopole
CellCan	Organisation québécoise des personnes atteintes de cancer (OQPAC)
Clinique Regain	Organisme gaspésien pour les personnes atteintes de cancer (OGPAC)
Coalition québécoise pour le contrôle du Tabac	Pancreatic Cancer Canada Foundation
Conseil pour la protection des malades (CPM)	PROCURE : Halte à la prostate
Consortium de recherche en oncologie clinique du Québec (Q-CROC)	Regroupement des aidantes et aidants naturels de Montréal (RAANM)
Dense Breasts Canada	Regroupement des aidants naturels du Québec (RANQ)
Espoir cancer de Lévis	Regroupement en soins de santé personnalisés au Québec (RSSPQ)
Factually Health	Réseau canadien des proches aidants
Fédération des cliniques privées de physiothérapie du Québec (FCPPQ)	Réseau canadien du cancer du sein (RCCS)
Fondation des étoiles	Réseau ROSE
Fondation rêver la vie	Sensibilisation VPH
Fondation du cancer du sein du Québec	Société de la LMC (leucémie myéloïde chronique)
Fondation sur la pointe des pieds	Société de leucémie et de lymphome du Canada (SLLC)
Fondation québécoise du Cancer	Swab the World
Fondation Virage	VOBOC (Venturing Out Beyond Our Cancer)

Final thanks:

The authors would like to thank all the patients, caregivers and organizations who actively participated and shared their experience so that this report best reflects the reality of people affected by cancer in Quebec.