

Second Survey Report on The Impact of the Measures Implemented to Counter the COVID-19 Pandemic on Oncology Patients

Written by:

Eva Villalba, MBA

Executive Director, Quebec Cancer Coalition

Dr. Marie-Pascale Pomey, MD, PhD

Professor, Health Management, Evaluation and Policy Department

Holder of the Chair in Assessment of Health Care Technologies and Intervention Methods

University of Montreal School of Public Health

Imane Guemghar

Medical student, Faculty of Medicine, University of Montréal

Marie-Andrée Côté

Patient-Partner, CHUM Hospital - Montreal

Catherine Wilhelmy

Patient-Partner, Patient-Partner Strategic Committee – Sherbrooke University Hospital
Research Center (CRCHUS)

June 26, 2020

Table of Contents

1. INTRODUCTION.....	3
2. METHODOLOGY	5
3. CONSIDERATIONS ON SEGMENTATION	5
4. DATA.....	6
Description of Respondents	6
Respondents' Situation Under the COVID-19 Crisis Context.....	11
5. PRESENTATION OF COMMENTS.....	29
Difficult situations.....	29
Impact on treatments	30
Fear of Contracting the Virus	31
Expressed Needs	32
Experience With Remote Consultations.....	33
Access to Medicines	35
6. DATA COMPARISON BETWEEN APRIL AND MAY 2020 CONSULTATIONS.....	36
7. MAIN FINDINGS	38
8. RECOMMENDATIONS.....	40
ANNEX.....	50
Annex 1: Survey Questionnaire	50
Annex 2: Recommendations from April 14, 2020 report and updates.....	58

"I don't know what I need anymore. I feel disengaged.

Mourning relatives, friends, mourning my life."

1. 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 the province, which aims to improve the health care system in Quebec for the benefit of those affected by cancer. More specifically, 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.

An initial survey was conducted in early April and its report was published on April 14¹. It highlighted the consequences of the pandemic on the physical and mental health of patients undergoing cancer follow-ups. Surgery and imaging tests were delayed by at least 4 to 6 weeks following the initiation of the emergency measures put in place at the end of March. Because of the many impacts observed, a second survey had been planned and was conducted six weeks after the first. Its objective was to observe the evolution of the impacts and refine the analysis of the needs of those affected by cancer, in order to inform decision-makers of the reality lived by patients in the field.

To monitor more clearly how the situation evolved, the Coalition decided to partner with its members and collaborators to create and disseminate this second survey. As guidelines for the fight against the pandemic change on an almost a daily basis, monitoring the evolution of the condition of patients receiving cancer care and services is relevant to inform current ministerial decisions and those of future governments.

The Coalition consulted its members in early May 2020, prior to the launch of the second survey. The main concerns raised were: the lack of a concrete plan to address the growing lists of people waiting for semi-urgent surgery, imaging and diagnostic tests; the Quebec Breast Cancer Screening Program being shut down; the temporary shutdown of clinical trials in oncology; the lack of flexibility to move treatment out of the usual locations (e.g., oral and subcutaneous treatments; infusion outside the hospital; home care); and the protection of vulnerable patients during hospital visits. The Coalition has also validated these concerns with health professionals in the field. In reading the various directives from the government, the Quebec Health Care Ministry and its subcommittee in oncology, it is clear that certain measures have been put in place to be preventive, proactive and anticipate the capacity of the health system to meet the needs of the population. Since the launch of this survey, many of the concerns cited have been partially

¹ [Survey Summary Report "Impact of COVID-19 Pandemic Measures on Cancer Patients in Quebec"](#) Pomey, M.P. ; Villalba, E. ; Taguemout, M. ; Ikene, D.L. ; Côté, M.A. ; Wilhelmy, C. April 14 2020.

or totally resolved, while others have yet to be addressed. The evolution of the recommendations will be addressed at the conclusion of this report and in the annex.

Despite the lack of up-to-date data, it is estimated by the Quebec Cancer Foundation that before the start of the pandemic, approximately 56,800 people in Quebec would be diagnosed with cancer this year². This represents 156 new cases per day. According to these statistics, 22,400 people will die from cancer (61 deaths per day). We have yet to observe whether or not these numbers will increase as a result of this pandemic, when we will be able to measure in real time the evolution of a disease that has been raging for decades. The concern shared by patient groups and health professionals is for vulnerable patients, including those in oncology, who are suffering collateral damage from this crisis, such as increased mortality rates. In other words, the concern is whether patients who would have been treated under normal circumstances could see their health deteriorate because of delays in access, which could lead to a fatal outcome.

This unprecedented health crisis has led the government to find solutions to remedy the situation and to put in place measures to protect the population. Indeed, we agree without the slightest hesitation that COVID-19 represents a real threat at the global level. Cancer now affects one out of every two people, it has been devastating for decades, and a vaccine against SARS-CoV-2 is not likely to be available for another 18 months. Furthermore, the only hope for people with cancer is to be diagnosed in time to extend their life expectancy and improve their quality of life. However, in the current situation, waiting times remains a concern and fluctuating guidelines are adding to the already high anxiety caused by the pandemic.

This report aims to consolidate our action to inform and influence the health policy decisions that will be taken from now on.

ACKNOWLEDGMENTS:

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.

² <https://fqc.qc.ca/en/information/the-cancer/statistics> *Based on 2010 data.

2. METHODOLOGY

This consultation was conducted from May 12 to May 26, 2020. The survey was shared on the Coalition's social networks and shared by its members on various platforms (Facebook, Twitter, LinkedIn) as well as through their mailing lists and electronic newsletters.

554 people answered the survey. However, only the following inclusion criteria allowed participants to continue the survey: patients under investigation; in active care or follow-up; in remission with or without follow-up and treatment. For some, relatives had to respond for them because of their condition. A total of **402 eligible respondents completed the survey** on the impact of the pandemic measures on people with cancer. 152 respondents had to be excluded as they did not meet the inclusion criteria.

The questionnaire consisted of 28 questions (see Appendix 1). For many of the questions, a comment section was provided, giving respondents the opportunity to share their views and concerns.

3. CONSIDERATIONS ON SEGMENTATION

The results presented are based on questionnaires that were fully completed. Initially, consideration was given to separating patients in “acute” care from those in “remission” for analysis. However, after reviewing the results, it appeared that the positions of those who indicated that they were in remission were not significantly different from those who indicated that they were in active treatment. In the majority of cases, these people have similar needs: imaging tests, screening, surgery, or follow-up (e.g., chronic but stable conditions such as chronic myeloid leukemia, myeloma, or to prevent recurrence). Very few people (n=8) who responded that they were “in remission” did not have regular follow-up, did not require testing or treatment. This finding highlighted the fact that patients, whether on active treatment or not, continue to **require access to the health care system** even after active treatment because they are at risk of recurrence or their immune systems require special attention.

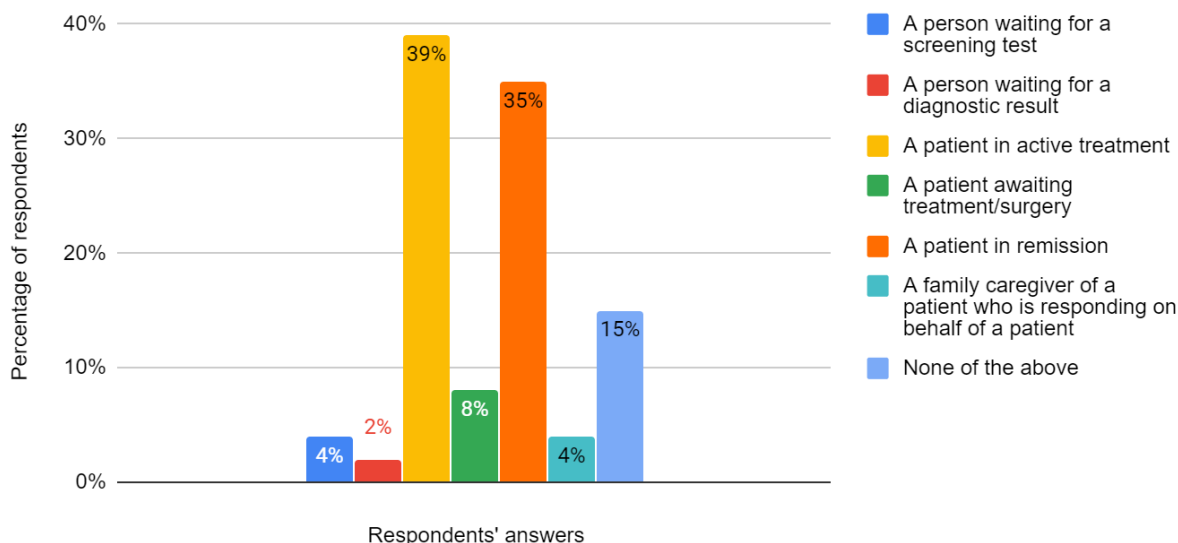
4. DATA

Description of Respondents

CARE PATHWAY

554 survey respondents answered this question. Of these, 39% are patients actively treated for cancer and 35% are patients in remission. It should be noted that 4% of the respondents, or 23 people, are not directly suffering from cancer, but answer on behalf of a patient as a caregiver. Approximately 15% of the individuals indicated that they did not belong to the proposed response options. These individuals were excluded from the remainder of the survey.

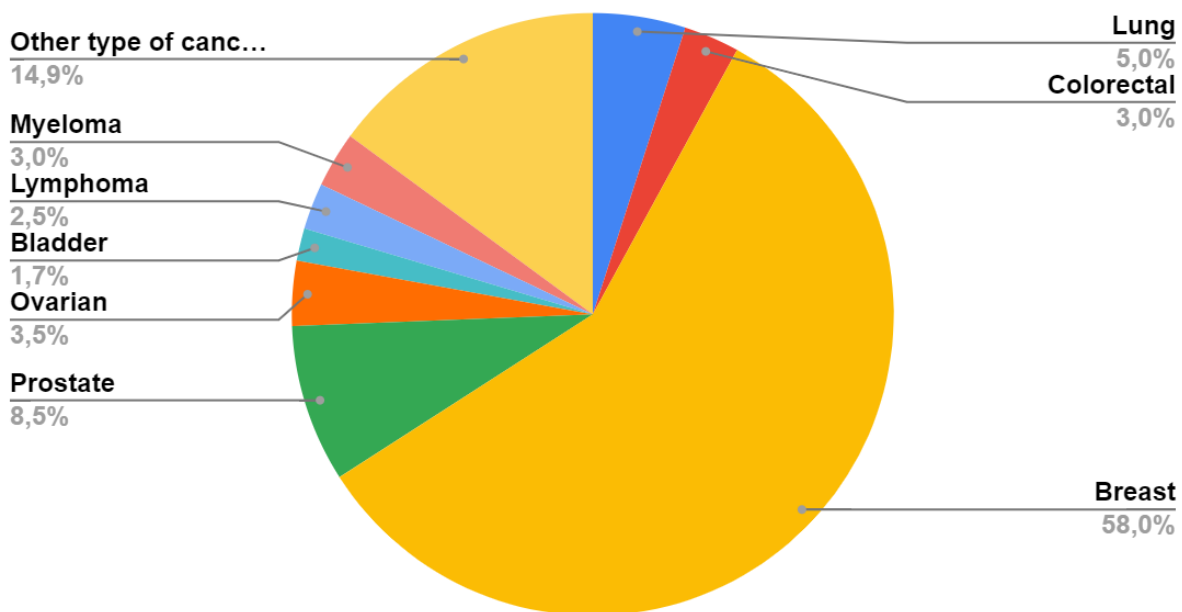
Profile of participants



1) TYPE OF CANCER

All respondents who met the inclusion criteria (402) indicated the type of cancer they had. The most common types of cancer were breast (58%), prostate (8.5%) and lung (5%). In addition, 15% of respondents have a cancer not identified in the choices available. It should be noted that patients may be at different stages of their cancer or even in remission. Others are still waiting for a definitive diagnosis.

Type of cancer



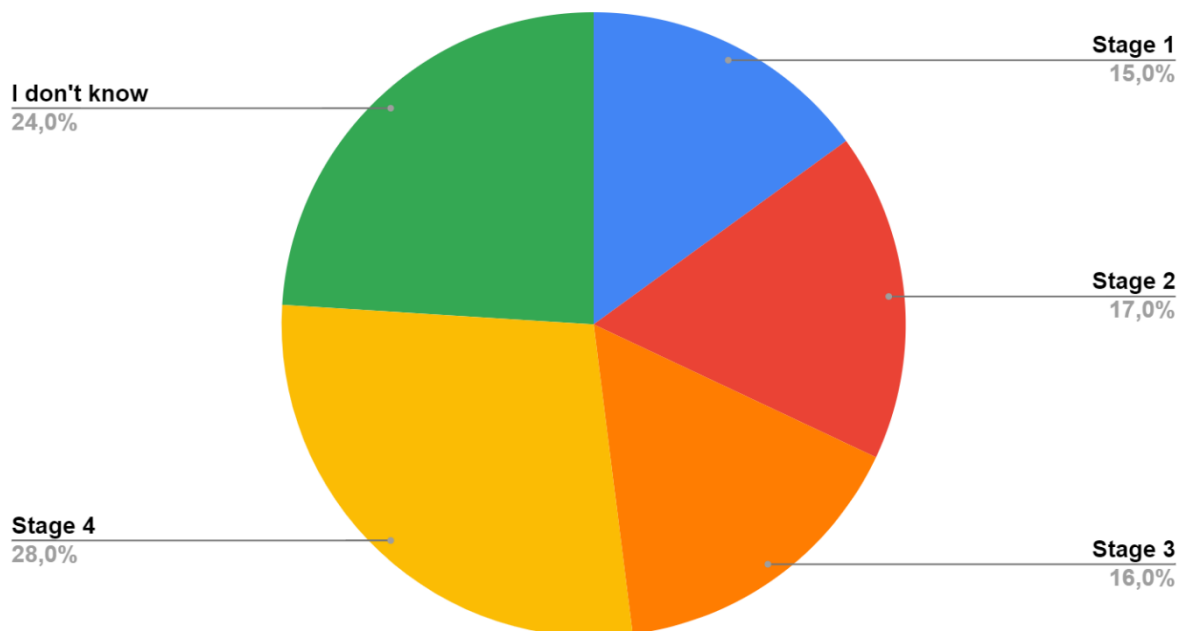
In our first survey, nearly 75% of respondents had breast cancer. An effort to reach a wider range of cancers was made for this survey. Nevertheless, the fact that breast cancer remains the most prevalent cancer in this survey can be linked to:

- a) The very wide distribution of the survey by the Quebec Breast Cancer Foundation and the Canadian Breast Cancer Network;
- b) Statistics: Breast Cancer is the third most common cancer in Quebec, and most common in women;
- c) The nature of deferred care and services: postponement of surgery, increased delays with the breast cancer screening program, and modified treatments due to COVID-19, disproportionately affect people with breast cancer.

2) STAGE OF CANCER

We note that 28% of the respondents are suffering from the most severe form of cancer, stage 4, and that the proportion of individuals suffering from stage 1, 2 and 3 cancers is similar with a rate of 15%, 17% and 16% respectively. It should be noted that nearly a quarter of the people who answered the question said they were not aware of the stage related to the severity of their cancer.

Stage of cancer

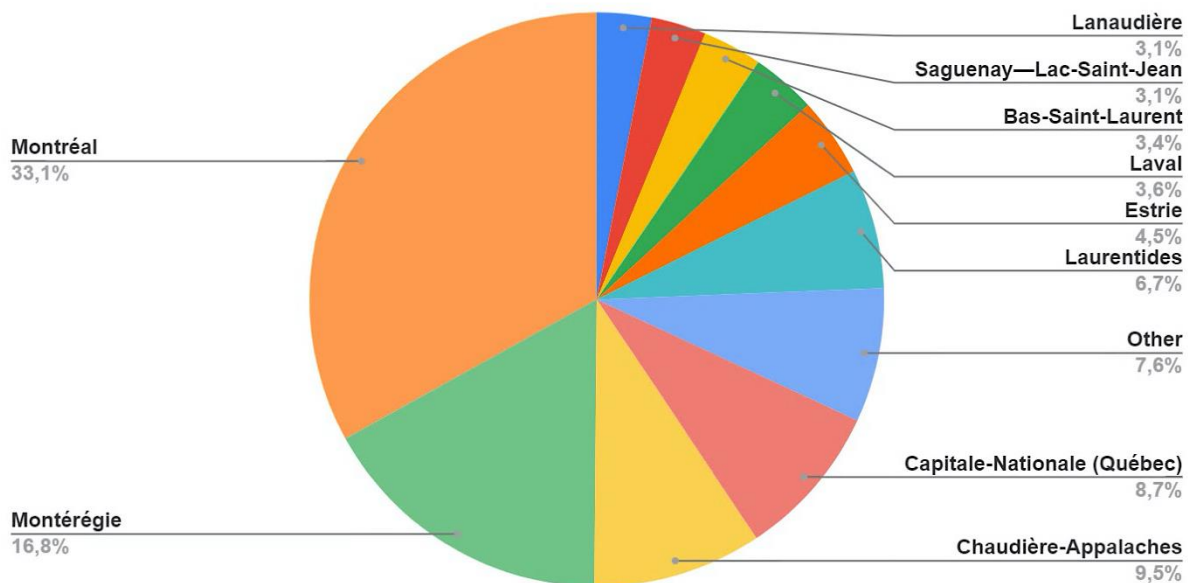


3) GEOGRAPHICAL ORIGIN

89% of the 402 participants answered this survey question. The Greater Montreal region is the most represented (53.5%) with 33.1% of respondents from Montreal, 16.8% from Montérégie, and 3.6% from Laval. The Quebec City region follows (18.2%) including 9.5% of respondents from Chaudière-Appalaches (a particularly high rate given its demographics) and 8.7% from the Capitale-Nationale.

The “Other” category includes the least represented regions, including: Côte-Nord (0,56 %), Gaspésie-Îles-de-la-Madeleine (0,84 %), Mauricie (0,84 %), Centre-du-Québec (1,40 %), Outaouais (1,40 %) and Abitibi-Témiscamingue (1,68 %).

Regional distribution of the participants

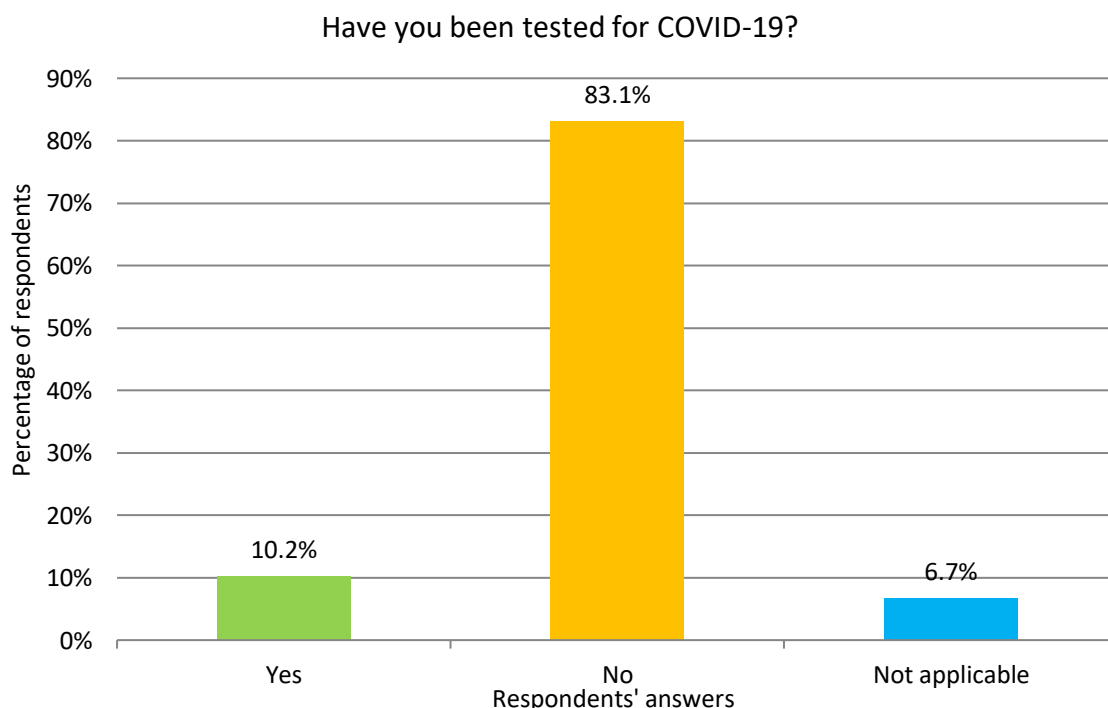


13) COVID-19 TEST

Considering that the initial INESSS guidelines related to cancer patients indicated the possibility of testing cancer patients before their appointment, a question was asked to validate the application and the actual frequency of this practice.

In the INESSS and Quebec Cancer Program guidelines, we find that *for screening and management of patient appointments : ensure COVID-19 assessment for all patients[...] before the scheduled appointment³, and it is recommended to call all patients who will be undergoing an examination the day before the examination to confirm the absence of symptoms/absence of isolation (return from travel or contact with an infected person) and to verify this same information upon arrival at the hospital centre. In the case of a positive questionnaire follow the recommendations in Table 1 and offer COVID-19 screening.⁴*

The vast majority of respondents were not tested for COVID-19: 83.1% answered “No” and 6.7% felt that the question did not apply to their situation. Approximately 1 in 10 participants were tested for COVID-19. Among those in active treatment, only 25 people were tested for COVID-19, or 6% of the total respondents. However, many commented that the test was negative.



³ https://www.msss.gouv.qc.ca/professionnels/documents/coronavirus-2019-ncov/20-MS-00496-41_pj_recommandations-generales-cancerologie-2020-03-19.pdf

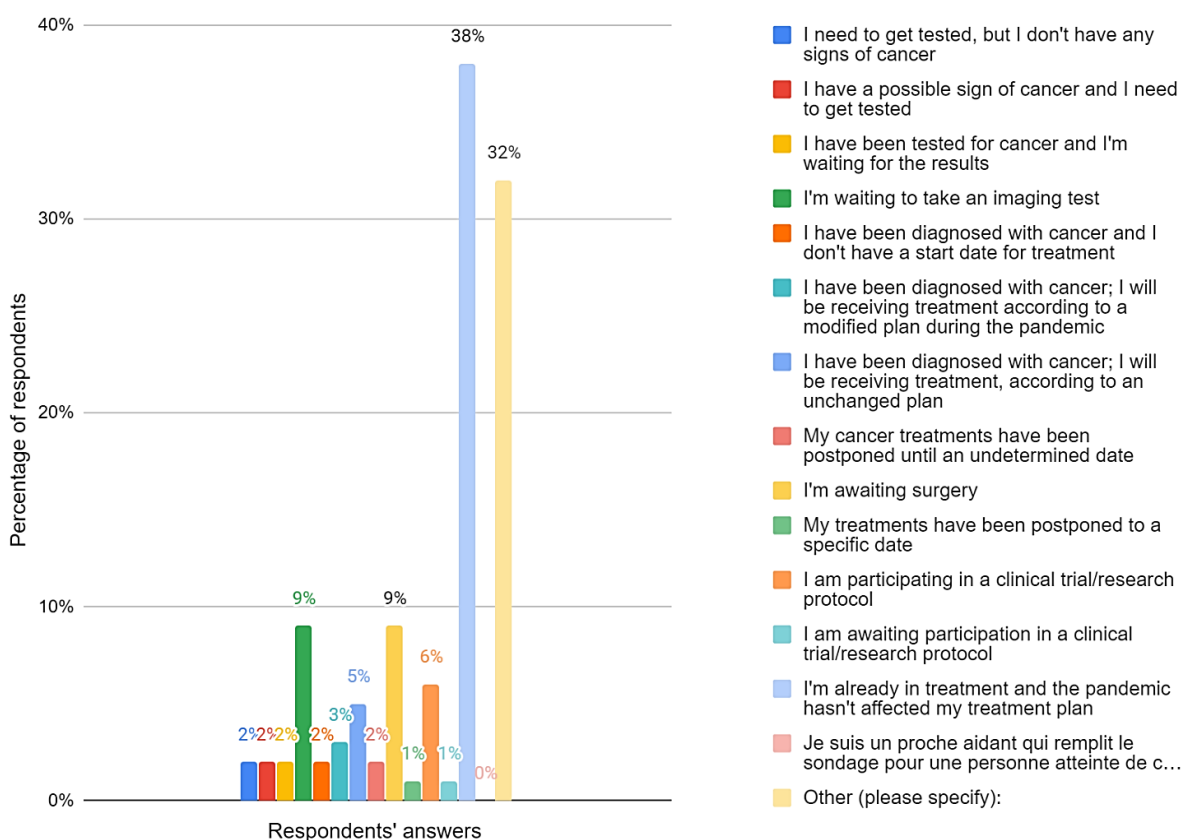
⁴ Translation of: ANNEX: Recommandations concernant l'impact de la covid-19 et les activités de dépistage et investigation du cancer du sein. MSSH March 17, 2020

Respondents' Situation Under the COVID-19 Crisis Context

1) FACING THE DISEASE

73% of respondents reported difficulties in accessing care, and 38% indicated that the pandemic has not affected their care (multiple answers were permitted). Many people are waiting for imaging tests (9%), surgery (9%), screening tests (2%), and other treatments (2%). Some are waiting until they can participate in a clinical study again (1%). As a result, several activities appear to remain suspended or postponed.

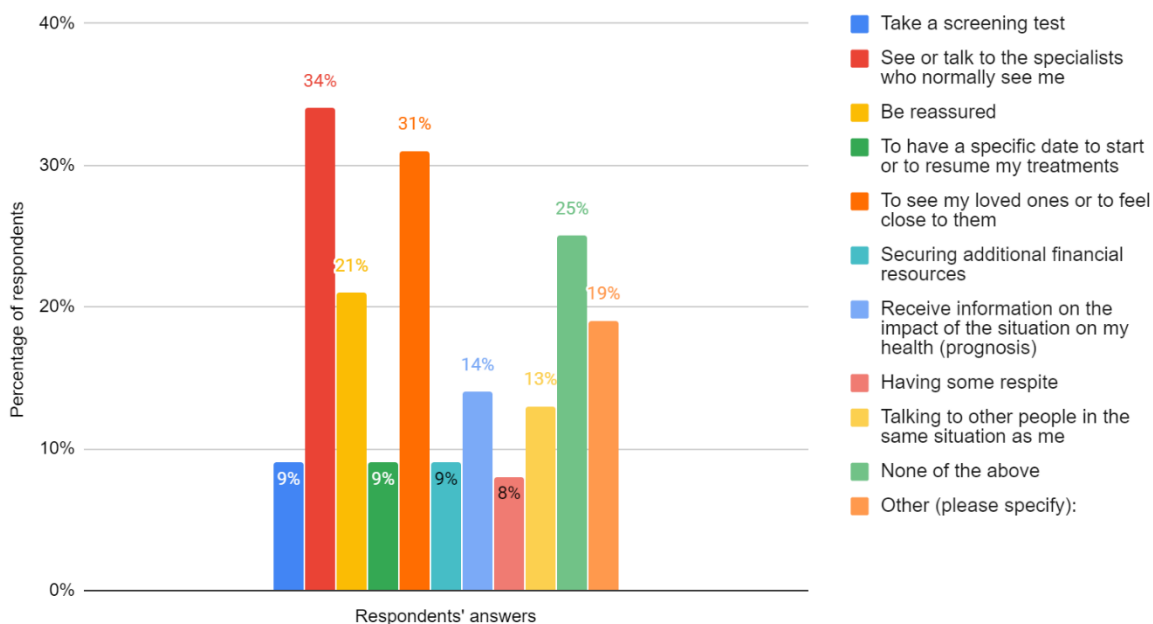
What is your current situation?



2) CURRENT NEEDS

The main needs of those surveyed were access to their specialist (34%), access to support from family and friends (31%) and reassurance (21%). In addition, 14% of respondents would like to understand how the current situation may affect their health status and 9% expressed a desire for a specific date to resume treatment. It should be noted that participants could choose more than one response.

What are your current needs?

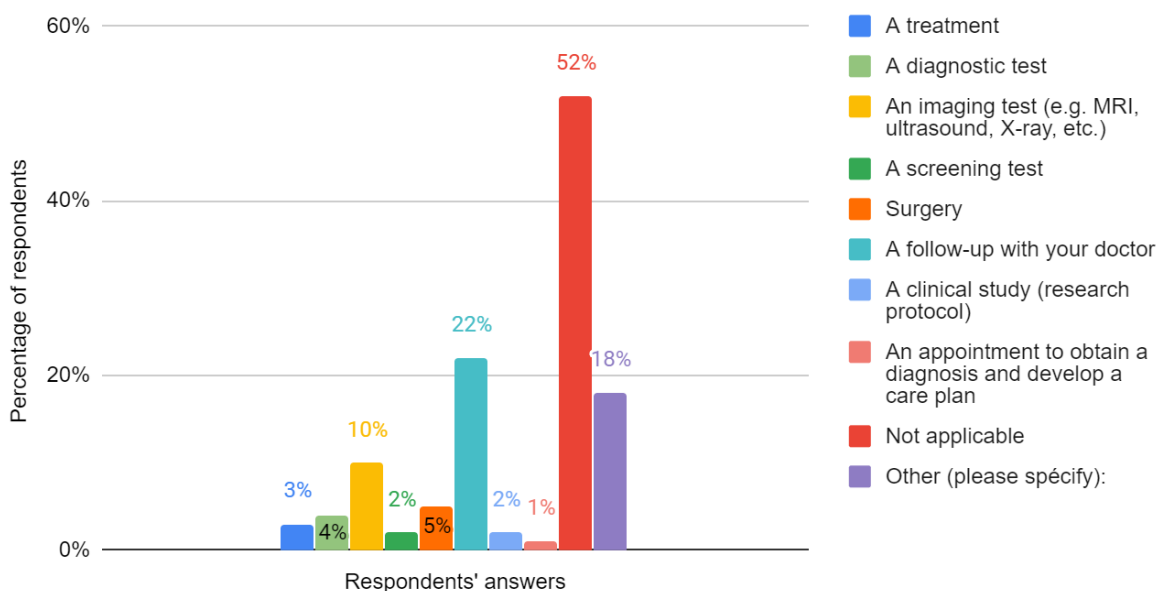


3) POSTPONEMENT OR CANCELLATION OF APPOINTMENTS

Approximately one person in five (22%) noted disruptions in their medical follow-up. 10% respondents also indicated that one or more of their imaging tests had been postponed. Surgery (5%) and diagnostic tests (4%) were also delayed. Looking at the individual results, most of the patients who had their imaging tests postponed were from the Montérégie region.

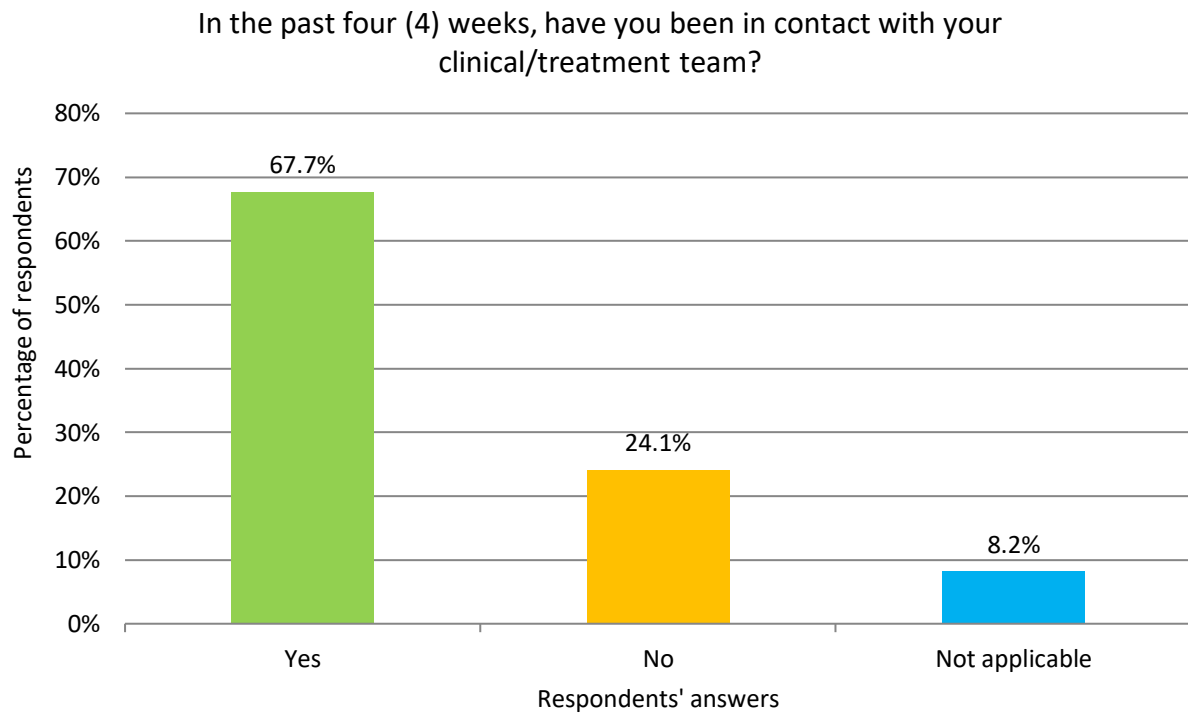
It is pertinent to note that the current circumstances did not affect the care plan for all patients. 52% of survey participants have responded that the question does not apply to their situation.

Rescheduled or cancelled appointment for :



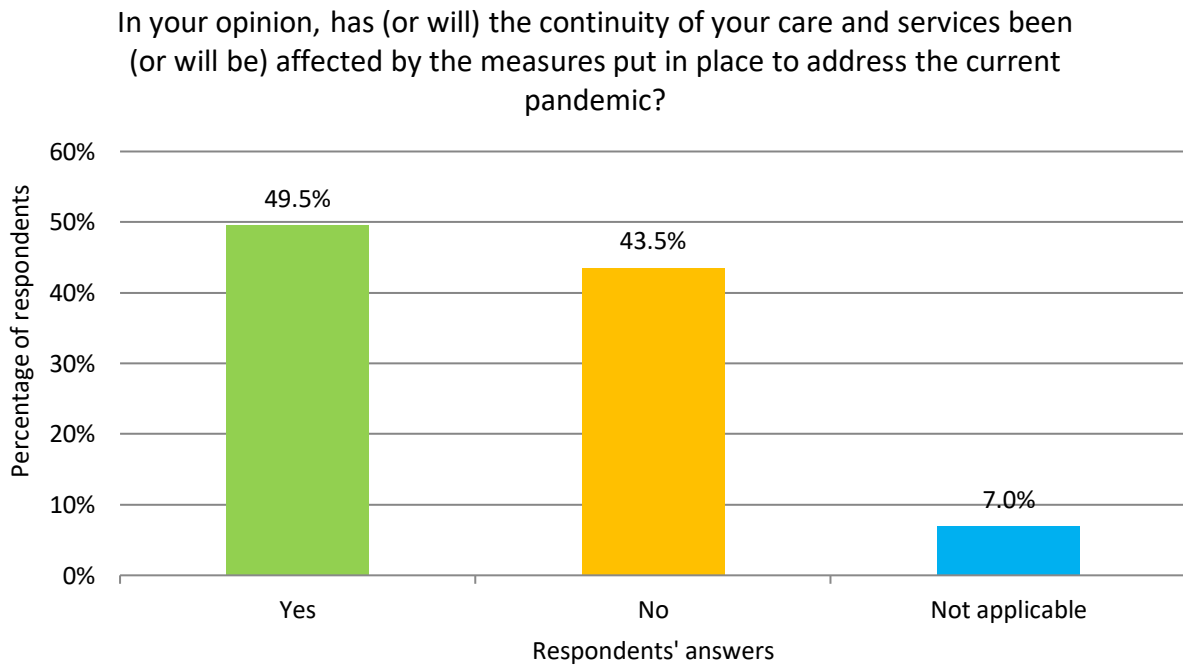
4) CONTACT WITH TREATMENT TEAM IN THE LAST 4 WEEKS

Of the 402 people who responded, 68% were in contact with their treatment team. Nevertheless, one person in four had not heard from their health care team in the past four weeks.



5) CONTINUITY OF CARE AND SERVICES

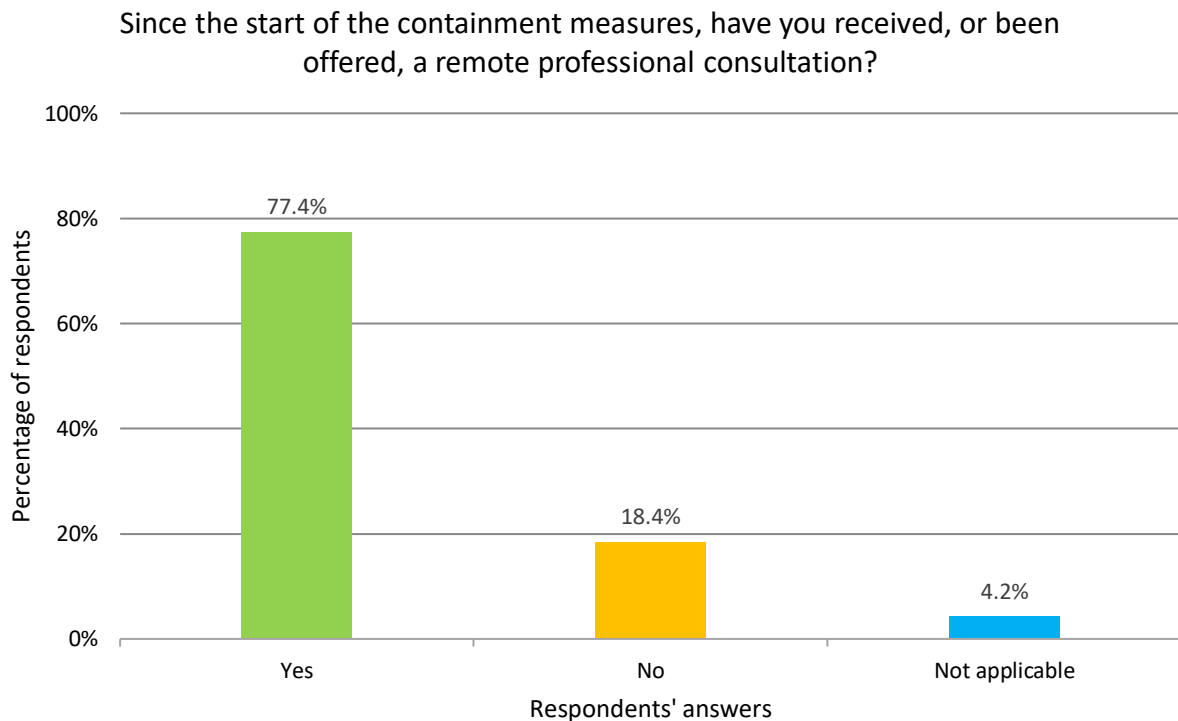
One out of two respondents (49.5%) feel that the measures put in place to deal with the COVID-19 pandemic have had (or will eventually have) an effect on the continuity of their care. 44% of the people surveyed feel that the continuity of their care has not been affected despite the pandemic.



6) SETTING UP A REMOTE CONSULTATION WITH A PROFESSIONAL

Most patients (77%) say they used remote consultation to get in touch with a professional. 18% of patients did not use remote consultations to contact a health care professional. This may be the case when the follow-up requires face-to-face interactions or physical examinations. In other cases, a remote consultation was simply not offered to the patient.

Note: 4.2% of respondents felt that the redirection of medical consultations to a virtual form did not apply to them.



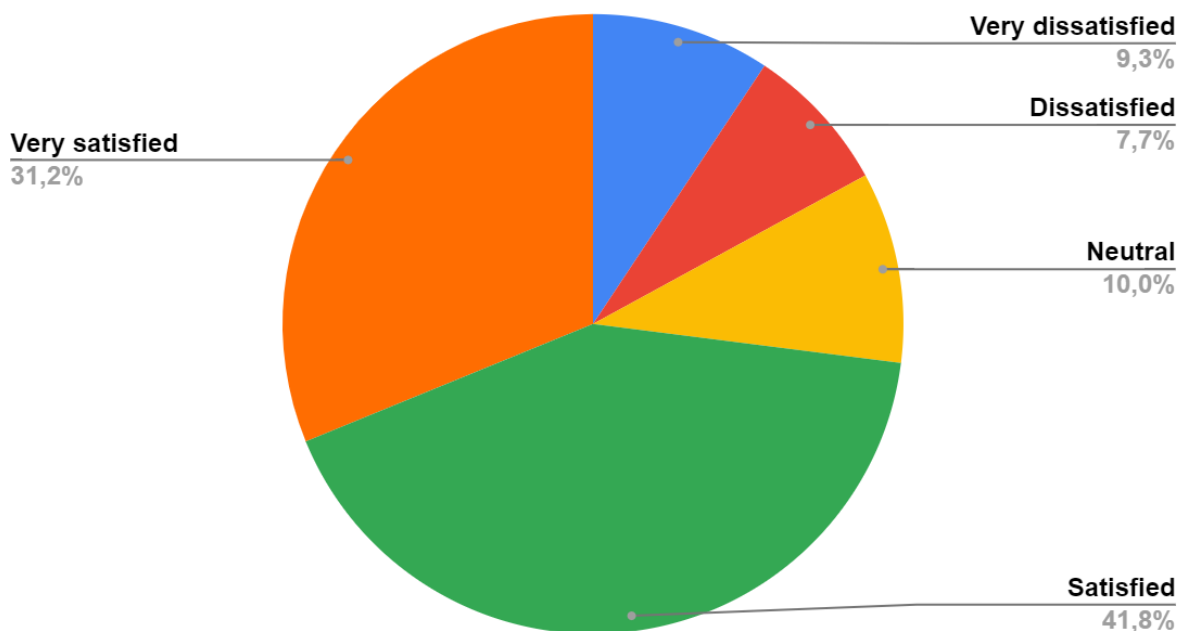
7) SATISFACTION WITH REMOTE CONSULTATION

This question allowed those who answered “yes” to the previous question to share their level of satisfaction. 72.45% of respondents said they were either very satisfied (31.2%) or satisfied (41.2%) with this new approach. Only 7.7% were dissatisfied and 9.3% were very dissatisfied.

The reasons for dissatisfaction given were related to interpersonal skills and the length of calls (calls too short or too impersonal). Others mentioned that they would have been more reassured to have a physical examination.

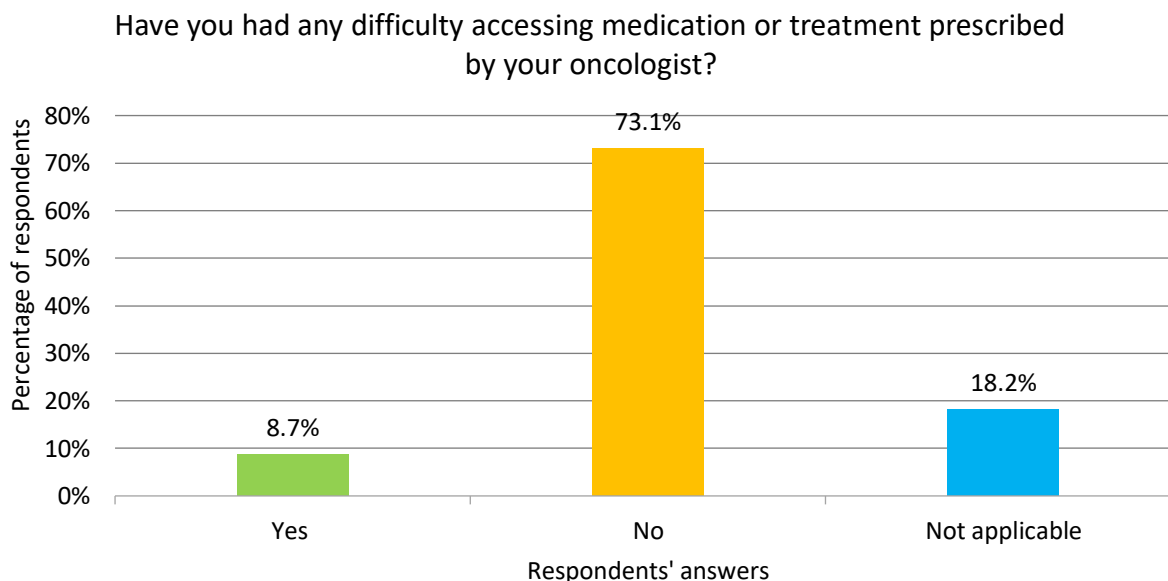
Several mentioned their preference for non-verbal communication, which is better in video conferencing than on the telephone.

Level of satisfaction with remote consultation



8) DIFFICULTY IN ACCESSING MEDICATION OR TREATMENT PRESCRIBED BY A PHYSICIAN

73% of respondents did not have difficulty accessing prescribed drugs and treatments for their cancer. However, nearly one in ten people had difficulty complying with their doctor's prescription due to reduced accessibility.



9) EXAMPLES OF MEDICATION OR TREATMENT

This response identified medication(s) or treatment(s) that had been in short supply or for which access issues had been raised. Of the 31 individuals who shared their access issues, the following medications were more difficult to acquire:

- Ibrance® (palbociclib)
 - Zoladex® (goserelin acetate)
 - Herceptin® (trastuzumab)
 - Letrozole
 - Darxalex® (daratumumab)
 - Xanax® (alprazolam)

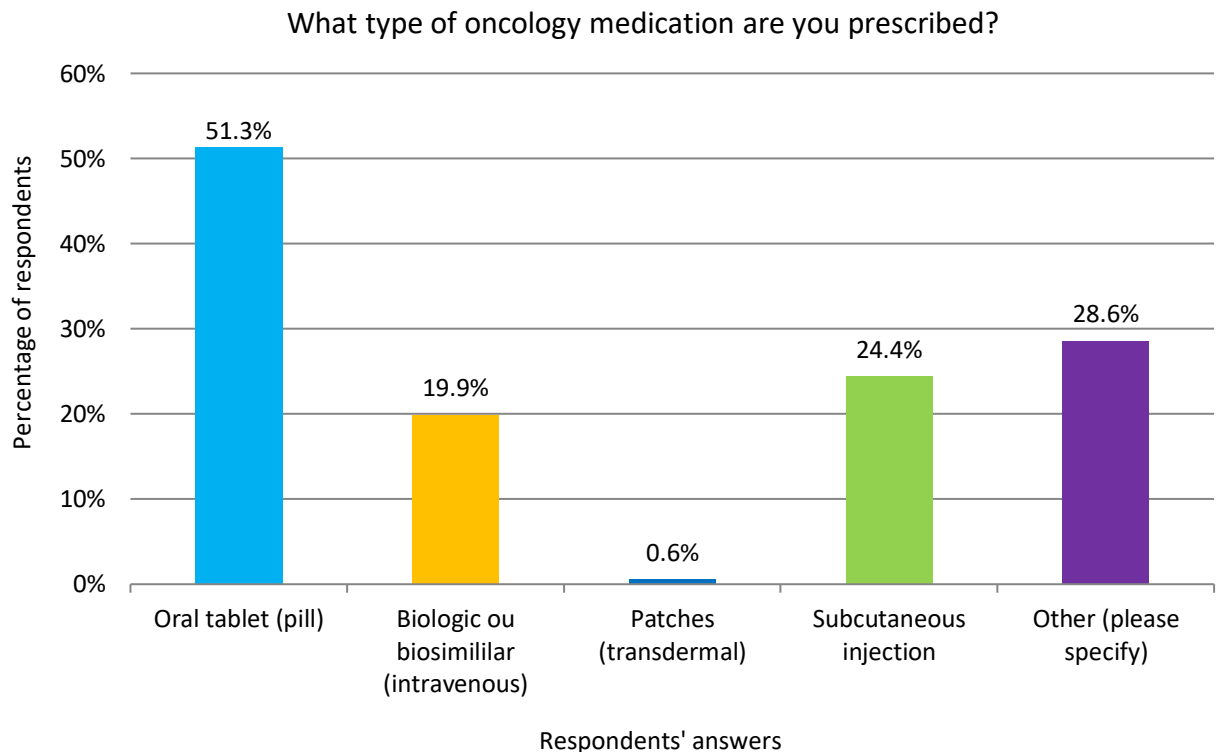
A few people who were dependent on treatments given in clinical studies were unable to access their medication (n=2).

10) ONCOLOGY TREATMENTS

More than half of the respondents (51.3%) take oral tablets as oncology drugs and some receive their medication in the form of subcutaneous injections (24%) or intravenous injections (19.9%).

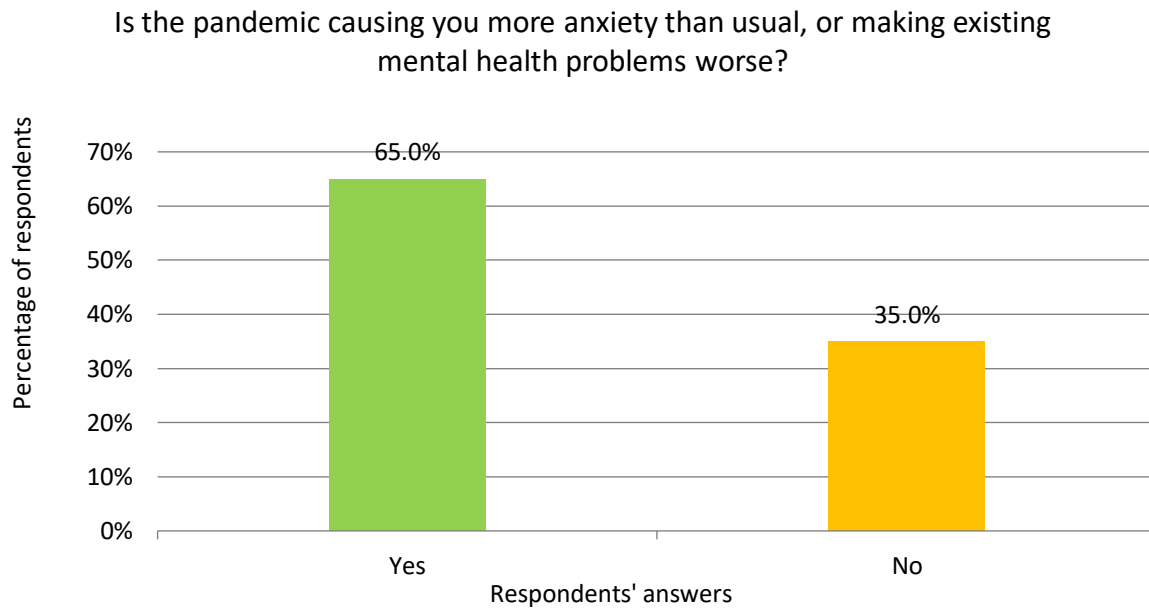
28.6% of respondents opted for “Other” - this category includes people who are not taking treatment, or for some of them, are treated with hormone or radiation therapy.

Because it was possible to select more than one type of treatment among the proposed statements, other forms of administration also had high response rates.



11) IMPACT ON ANXIETY

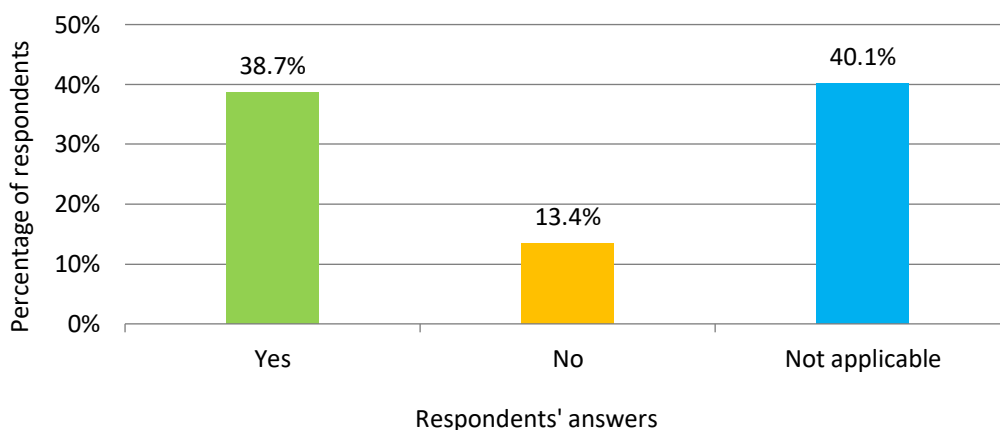
65% of respondents said that the current COVID-19 pandemic contributed to their psychological discomfort by increasing their anxiety or aggravating their pre-existing mental health problems, while 35% felt that the pandemic did not have an adverse psychological effect on them.



12) PHYSICAL PRESENCE OF CAREGIVERS

In the past 2 weeks, 39.7% of respondents had a caregiver physically present and 13.4% did not. 40% of the people who answered this question felt that this question did not apply to their experience, possibly because they did not have a caregiver.

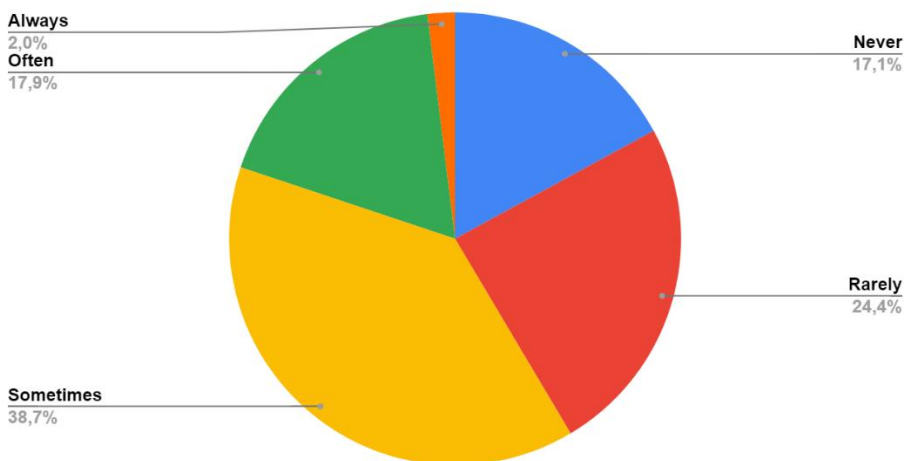
During the last two (2) weeks, my caregivers have continued to be physically present with me:



13) MANAGING ANXIETY

19.9% of respondents said they often or always felt anxiety in the last two weeks, while 24.4% said they rarely or never felt anxiety (17.1%).

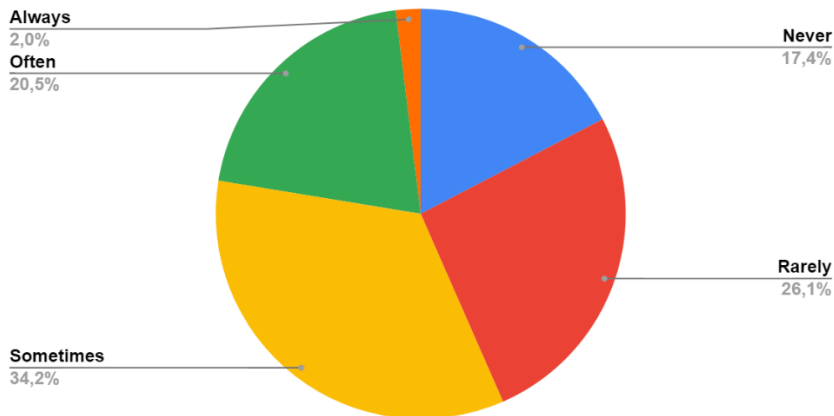
In the past two weeks, I have found it difficult to focus on anything other than my anxiety...



14) MANAGING WORRY

Respondents rated their level of worry over the past two weeks. About 1 in 5 (22.5%) said they are often or always overwhelmed with worry. Most respondents, 34.2%, indicated that they are worried only sometimes. Many participants seem to be able to manage their worries more easily, saying they are rarely (26.1%) or never (17.4%) worried.

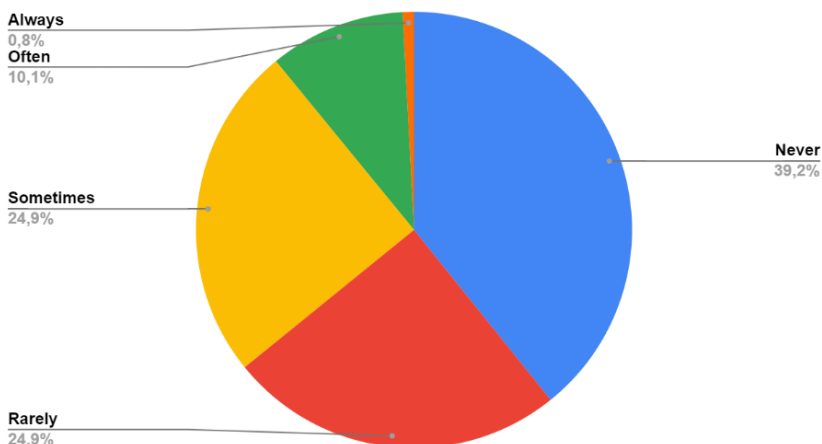
In the past two weeks, I have been overwhelmed by my preoccupations...



15) PERCEPTION OF DESPAIR

Despite the anxiety and worry, few people have been significantly desperate about their situation in the past two weeks. Indeed, in the last two weeks, 39.2% of participants indicated that they had never felt despair and 24.9% said they rarely experienced such an emotion.

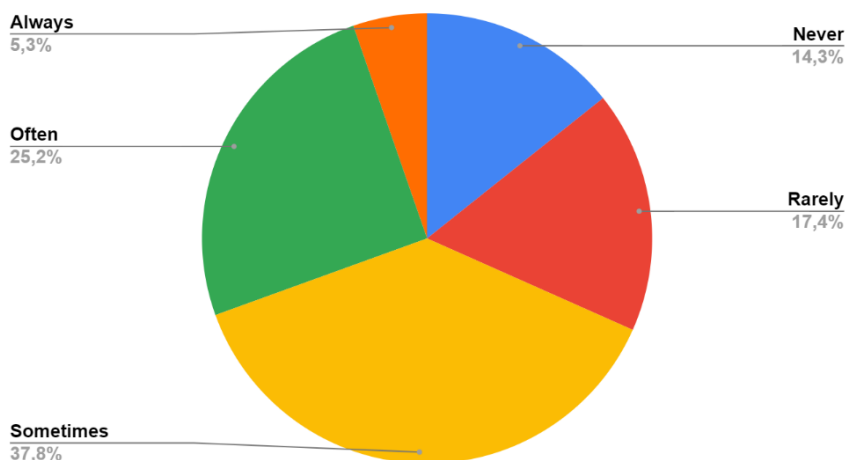
In the past two weeks, I have felt desperate...



16) PERCEPTION OF ISOLATION

30.5% of respondents said they often (25.2%) or constantly (5.3%) experience a feeling of isolation. 37.8% experience it sometimes, while 17.4% rarely felt it and 14.3% never felt it.

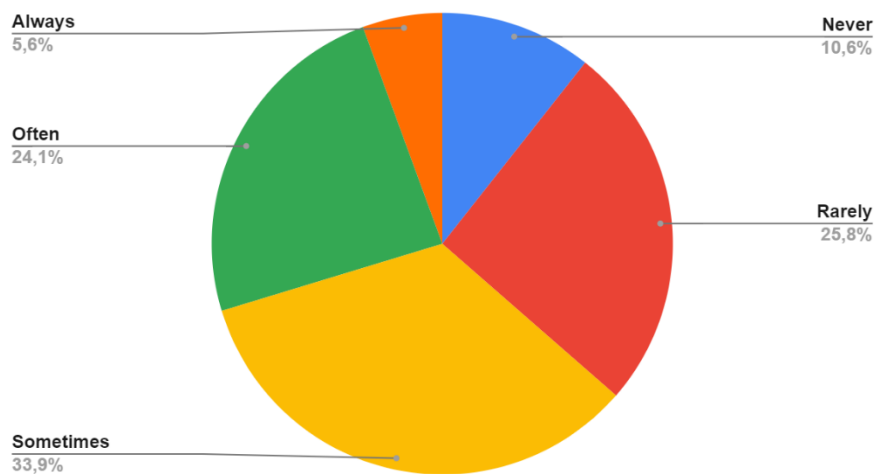
In the past two weeks, I have felt isolated from the others...



17) SLEEP DISTURBANCE

In the past two weeks, nearly one third (29.7%) of respondents had difficulty falling asleep often (24.1%) or constantly (5.6%). A little more than one third (33.9%) experience it sometimes, while the other respondents (36.4%) experience it rarely (25.8%) or never (10.6%).

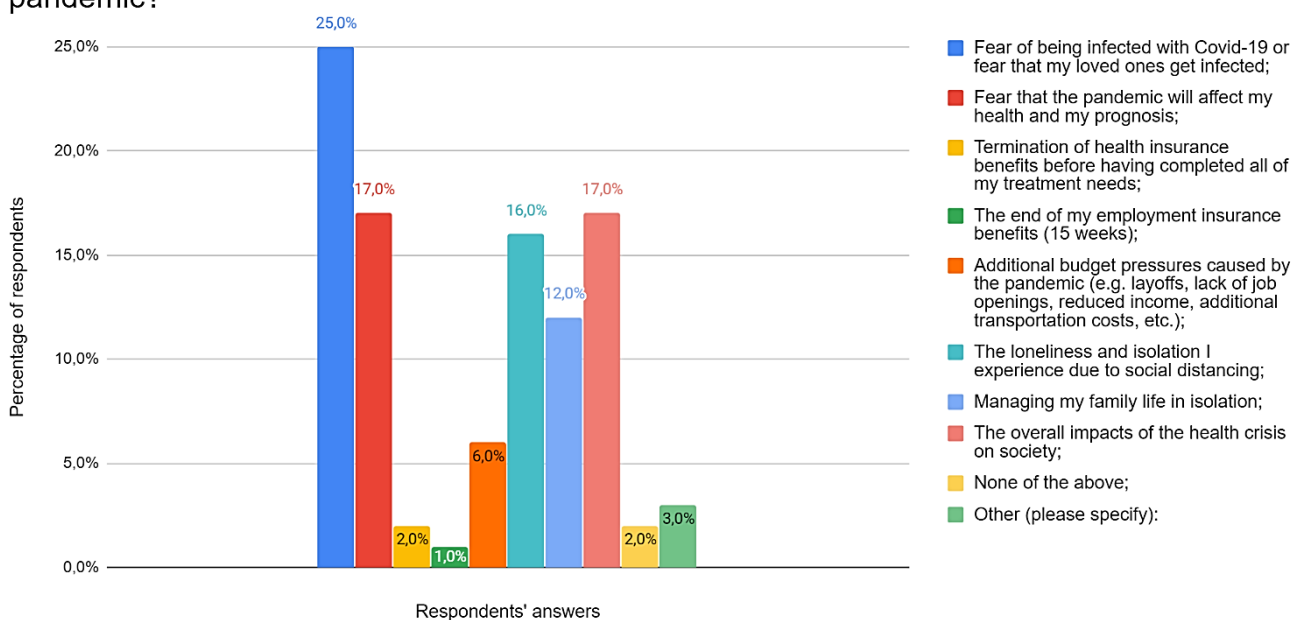
In the past two weeks, I have had difficulties falling asleep...



18) ADDITIONAL ISSUES OR CONCERNS

A quarter of the 357 respondents who answered this question (25%) expressed fear of contracting or having a close relative contract COVID-19. Another concern is the fear that the pandemic will affect their health (17%) or society (17%). The psychological impacts of isolation were mentioned by 16% of those surveyed. In addition, many people (6.0%) indicated that they have financial concerns related to the health crisis, such as layoffs, lack of job openings, reduced income, and additional transportation costs.

Other issues or concerns related to the measures put in place to address the COVID-10 pandemic?



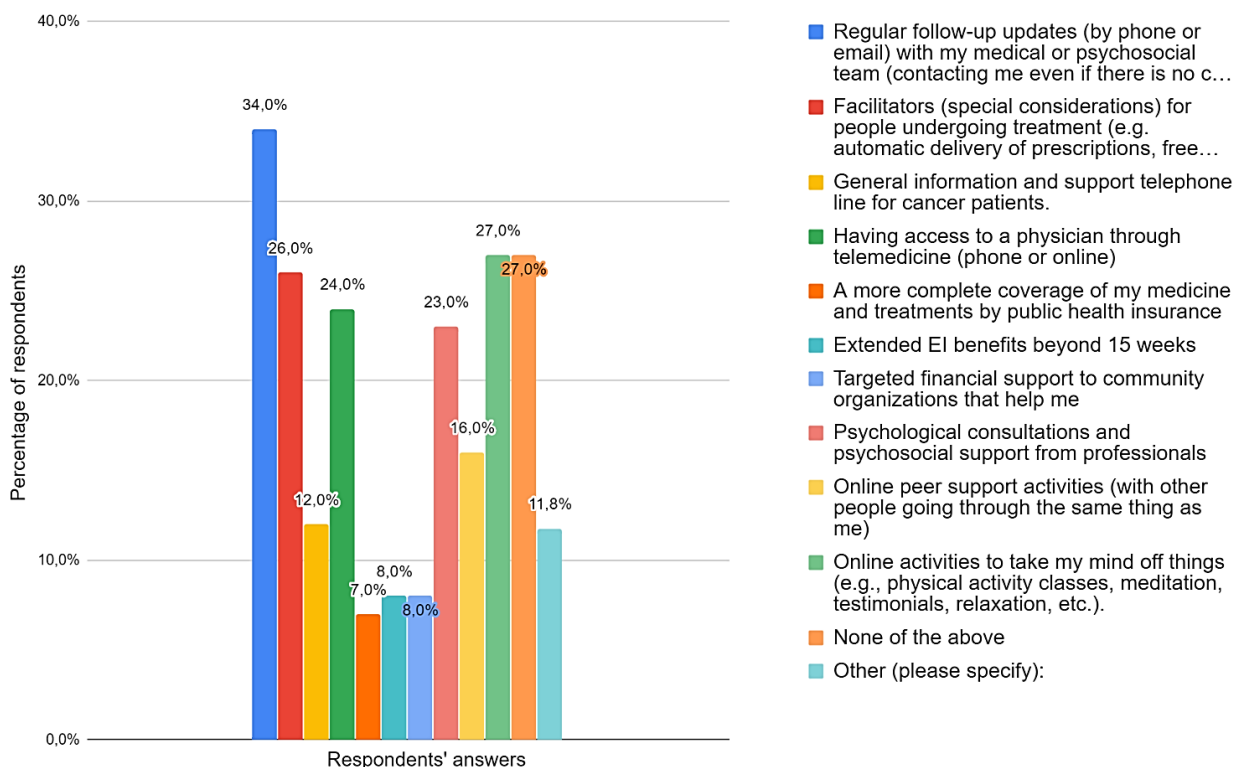
19) SERVICES OR ACTIONS TO BE PUT IN PLACE TO HELP PATIENTS BETTER COPE WITH THE PANDEMIC PERIOD

Four main dimensions emerge as priorities for patients regarding the services or actions they would like to see put in place that would help them through the pandemic:

- a) regular follow-up with the medical or psychosocial team (34%);
- b) online recreational activities to distract themselves (27%);
- c) access to a doctor via tele-medicine (24%);
- d) psychological consultations or psychosocial support with professionals (23%).

The other solutions proposed are: the establishment of a telephone support and information line (12%); peer support activities (16%); more comprehensive drug coverage (7%), extended EI benefits beyond 15 weeks (8%) and one-time financial support from a community organization (8%). 38.8% of individuals responded to none of these proposals (27%) or other (11.8%).

Services or Actions to be Put in Place to Help Patients Better Cope Through the Pandemic

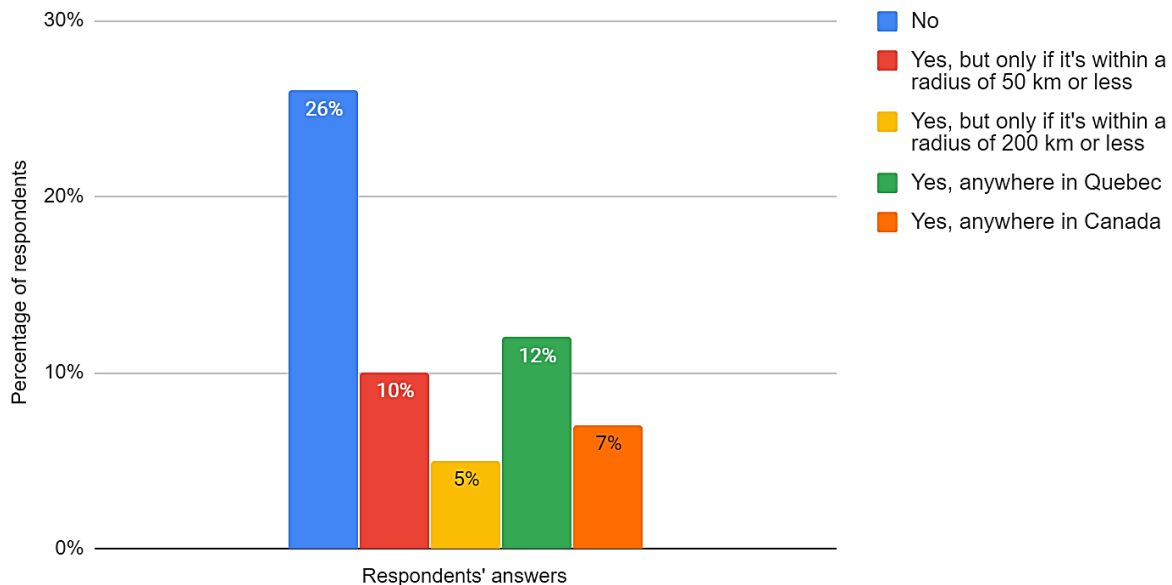


20) TRAVELLING TO ANOTHER AREA FOR SURGERY OR TREATMENT

Regarding the openness of patients to travel for faster access to their treatment, surgery, or clinical trials, 40% of the individuals who answered the question felt that this was not relevant to their situation. As the respondents concerned represented 60% of the people who answered this question, the results were carried over to this proportion of respondents.

Among the respondents concerned (60%), nearly half would not travel (43%) while the others (56%) would be willing to travel a certain distance to access surgery or treatment that would not be available near their home. The distance each would be willing to travel in such a scenario varies: 16% would travel no more than 50 kilometres, 20% would travel anywhere in the province, 11.6% would travel anywhere in Canada if necessary, and 0.8% would travel no further than 200 kilometres. Respondents therefore confirm that they would be willing to travel to access surgery, treatment, or clinical trials. A certain number (n=9) mentioned that they already travelling for treatment.

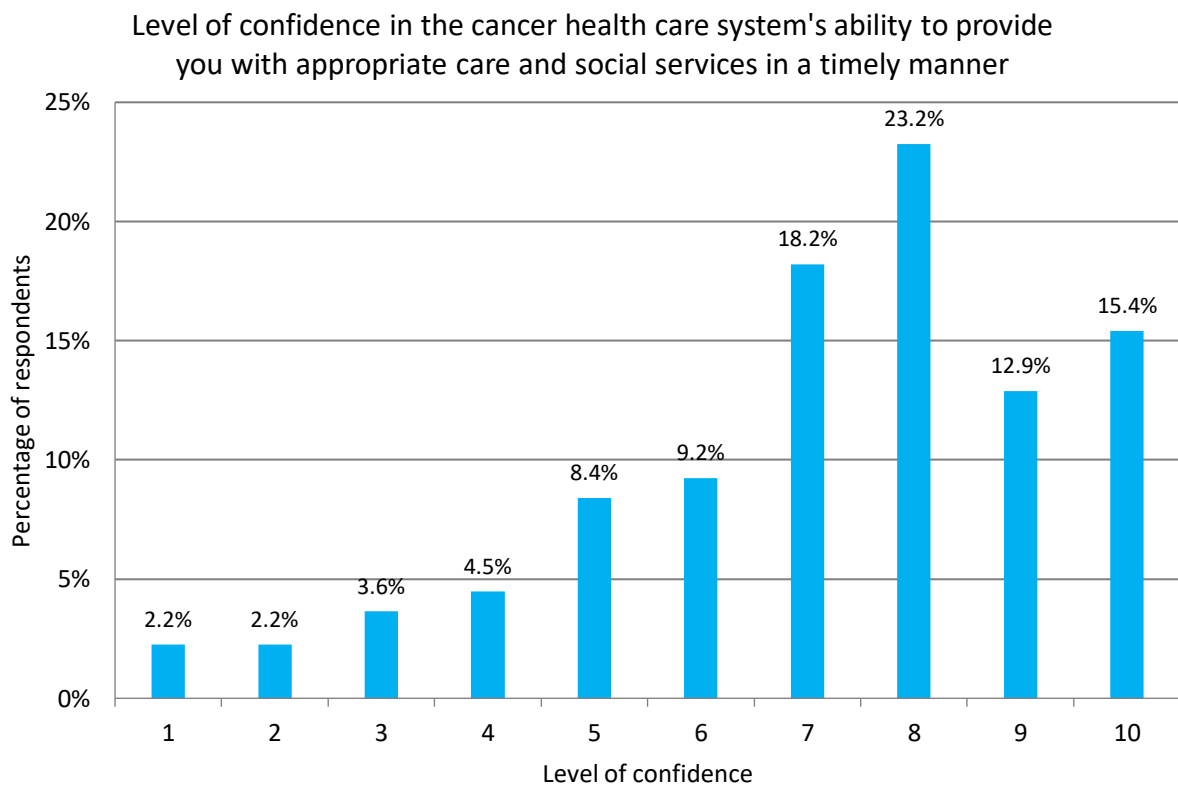
Would you be willing to travel to another region to gain quicker access to surgery or treatment that is not currently available in your usual health care facility because of COVID-19?



21) CONFIDENCE IN THE ABILITY OF THE HEALTH CARE SYSTEM TO PROVIDE TIMELY AND APPROPRIATE CARE AND SERVICES

The next question asked survey participants to express their level of confidence in the health care system regarding the delivery of cancer care by rating on a scale of 1 to 10. A score of 1 indicates no confidence in the health care system while a score of 10 indicates full confidence.

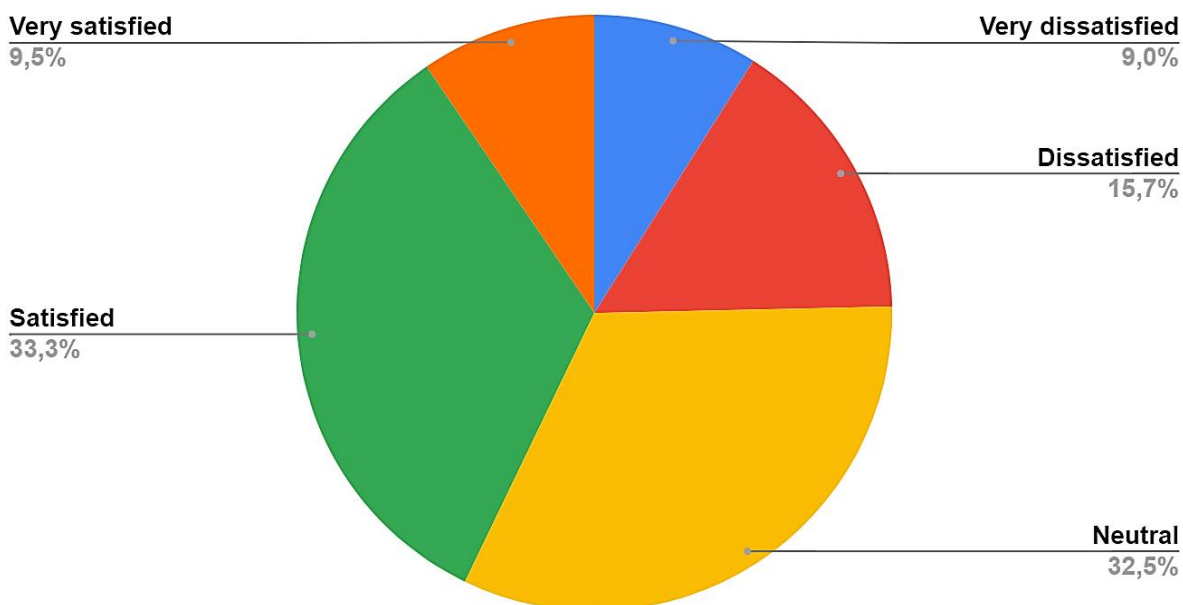
89% of respondents completed this question, with a mean score of 7.2 and a median score of 8. Over 51% of respondents rated the health care system 8/10 or higher. The cancer patients surveyed are therefore quite confident that the health-care system will be able to provide them with the necessary care and services when the time comes.



22) SATISFACTION WITH MEASURES TAKEN BY THE QUEBEC GOVERNMENT

42.8% of respondents are satisfied (33.3%) or very satisfied (9.5%) with the measures put in place by the provincial government to allow follow-ups for people affected by cancer. Approximately one person in four is moderately (15.7%) or strongly (9.0%) dissatisfied with the measures currently in place. 32.5% are neither satisfied nor dissatisfied.

How satisfied are you with the measures put in place by the Government of Quebec regarding the care of persons affected by cancer?



5. PRESENTATION OF COMMENTS

Respondents to the questionnaires were given the opportunity to supplement their responses with comments. Here we present a summary according to the themes that emerged after a qualitative analysis of these comments. These themes relate to: the situations that were deemed difficult; the impact of the crisis on treatment; the fear of contracting the virus; the needs expressed by the people surveyed; the way in which remote consultations are experienced; and the impact on access to medication.

Difficult situations

Physical distancing has led to social distancing that has been difficult for patients to live with:

"I can no longer travel to visit my family."

"This is THE time in my life when I need help and I need someone to take care of me and right now no one can take care of me. I can no longer see my family or friends."

"Not being able to go into the pharmacy to talk to the pharmacist. Not being able to be accompanied by my husband to my treatments."

And created a lot of anxiety:

"We must be alone for all treatments and surgery. It's inhuman."

"I'm more anxious and very fearful."

"I'm experiencing containment stress. I lack contact with my family. I cannot walk."

"I have a lot of anxiety knowing that the tumour is progressing and that nothing CAN be done, even though there are solutions. Sleep is severely compromised for both my spouse with cancer and me, the caregiver."

"My anxiety level is high in relation to the fear of contracting the virus. I'm immuno-suppressed and having lung metastases, I don't feel comfortable with the idea that I may be the one who won't be reanimated given my prognosis."

"I'm experiencing more anxiety than usual, I'm sadder."

"Being more at risk due to the disease is a source of stress for me. I need to be more careful."

Patients are looking forward to being out of the situation and finally be able to see their loved ones and have physical access to their health care professional:

"I can't wait to get out and not always be afraid as an immuno-suppressed person to be in contact with others who don't take it seriously."

Patients also find it difficult to reschedule appointments without an specific resumption date:

"Getting my mammogram, which was scheduled for April and was postponed, and meeting my doctor. I'd like to reschedule my appointment."

"I'm worried about the postponements. I'm afraid my condition will change."

"I'd like to stop postponing routine tests like blood tests and ventriculograms..."

"I'm finding it difficult to reschedule my mammogram and follow-up with my specialist."

"A longer wait time for the PET scan and a delayed follow-up appointment for the final answer as to whether I can return to work as a nurse myself, the delays have increased my concern and is delaying the process of ending the disability if there is a possibility."

"I filed a complaint about a six-month delay in my MRI follow-up."

"I can handle the uncertainty of the pandemic, but when I think about the possible delay in my follow-up MRI, it causes me additional stress..."

"My March 16th mammogram appointment has been cancelled and has to be rescheduled again."

"If other appointments are cancelled, such as for blood tests, it can happen that a new cancer or even a recurrent cancer goes unnoticed."

And some still feel abandoned:

"I feel like cancer care is second only to the possibility of a COVID infection. My chances of surviving COVID are much higher than my chances of surviving this cancer."

"I feel abandoned."

Impact on treatments

Regarding the current situation experienced by patients, we have documented their response in a variety of situations. These range from situations where treatment was not affected at all to dramatic situations where the person felt that they were not respected:

"I am receiving my treatments as originally agreed."

"I was diagnosed during the pandemic and treatment started immediately."

"I'm in chronic treatment, my plan has been changed."

"My bone marrow transplant has been postponed. I must continue my chemotherapy."

"I'm waiting for a follow-up and I haven't had any updates yet."

"I got my medical appointment over the phone. My cancer diagnosis over the phone and my diagnosis of incurable cancer over the phone."



"In addition to the chemo treatments, all other care and treatments have been cancelled: masso, physio, osteo, home help and social support from the CLSC."

Several patients shared examples of how their treatment was changed in this context:

"My surgery was cancelled, so I had to opt for preventive treatment while I was waiting and therefore the operation has been postponed for at least 7 months, but who knows if in 7 months there will be a wait even for surgeries where there was practically no wait?"

"Without hormone therapy, I feel more at risk of cancer coming back."

"Instead of 25 treatments I received 15, I hope that this will not affect the rest of the cancer."

"The measures applied during chemo treatments have changed and I wish I had been informed before, as it was quite stressful during and after treatment. The side effects are similar, and I was isolated during treatment and when I asked them why, I didn't get clear answers."

Fear of Contracting the Virus

Patients are also afraid of contracting the virus and are genuinely concerned about the behaviour of citizens who do not respect public health rules from their point of view:

"I have to go to the hospital for a blood test in June. I'm worried about the possibility of an infection."

"More safety on the streets, on the sidewalks; generally speaking, people, children, young and old don't pay any attention at all (especially runners); and the bikes start to roll.... it won't be fun; Not to mention that many people don't wear masks in cramped places like grocery stores."

"To know whether or not, in the event of contamination, cancer patients in active treatment are or are not being received and treated separately from the rest of the population. It's a bit worrying to go to hospital for blood tests, treatment, and examination".

"When I go to the hospital for treatment, I develop a phobia of the elevator button and the government's deconfinement measures are not very consistent and do not demonstrate the seriousness of this virus, which causes me even more stress. Especially when I read the latest scientific research and see that there is no systematic sampling and screening test for all essential workers."

"A voice for us in the media and with governments. They only talk about the elderly, not about us with weakened immune systems. I have to make several arguments to the information officer at the hospital to make a phone call to my spouse who is waiting in the parking lot to pick me up at the door because he wants me to use the pay phone, even though I tell him I can't because of my immune system. The government does not take

the virus and its consequences seriously and it is being spread in the population. Since going back to work, my sister told me that her husband had not respected the wearing of the mask and the distance at the plant and the foreman looked at him and said nothing. That was only a week after he returned to work. Going to the hospital creates anxiety that I didn't have before. It also makes me careful."

To avoid contact with institutions, more and more alternatives to treatment are being implemented, such as home follow-up by the CLSC for blood tests:

"I had blood tests taken by a home care nurse."

"The blood samples were taken by my CLSC instead of going to the hospital."

"I have several home care services and my hospital appointments are very limited (only the essentials like my scans)."

Expressed Needs

Patients identified that they had psychological support needs. Some of them were able to benefit from it:

"Luckily, I'm being monitored virtually by the oncology psychologist. Cancer centres offer very good online activities, like Hope and Cope and the West Island Cancer Wellness Centre."

"All of the above would help meet the individual needs of patients. Each of us has both similar and different needs."

"Weekly spiritual webinars for six weeks by the oncologist and the psychiatrist."

For others it was more difficult:

"I've asked for psychological support, I'm still on hold. I was diagnosed with cancer in February and the pandemic arrived in March. It creates a lot of insecurity for me."

"The delays and lack of psychological support have been difficult."

"I'm uncomfortable with phone appointments. I have to do this with my psychologist and I find it more difficult."

It also appears that access to exercise programs has not been easy to maintain for some patients:

"[For the past ten weeks, it has been difficult for me to access] my physical exercise program, which is essential for my physical and mental well-being."

Or support groups whose activities have been suspended:

"On the other hand, we don't have access to any of the services set up like the support groups."

Respondents also identified the need for treatment information:

"[I need] information on the progress of my treatments."

"The measures applied during chemo treatments have changed and I wish I had been informed before, as it was quite stressful during and after treatment. (The side effects are similar and I was isolated during treatment and when I asked them why, I didn't get clear answers."

And some shared needs for financial support:

"In addition, I have just lost my job that I had for 2 years and which was stable, so financially I am more stressed by the situation."

One person recounted their dismay at the impact of the pandemic on different facets of their life:

"I find it very difficult not to be able to be accompanied, even though this is my third cancer and I am tired. Also, many of the medications I must take are not covered and I need financial help. It's unfair to have paid so many taxes, to have two master's degrees, to have lost my job because of cancer and to have had to use all my investments, sell my assets to pay expenses related to cancer treatment and to find myself at 49 years old on social assistance. On top of that, I am alone for my treatments, surgery, etc., because it is not allowed during the pandemic, it is inhuman."

Experience with Remote Consultations

Patients have testified that for the past four weeks, their consultations, which are normally conducted in person, have been primarily by telephone. Many patients indicated that they had been seen in a tele-consultation. These consultations are with doctors, physiotherapists, nurses. Most often people found their experience to be positive. Professionals also communicate with their patients by e-mail.

"I love it, I don't have to go anywhere. I'm an hour and a half away, so I save at least three hours in the car."

"Since April, my follow-ups with my oncology doctor have been done by phone. However, if I need to see him in person, it is possible on request."

"Not for oncology. I had an appointment with a gastroenterologist (first consultation) and it was done over the phone rather than in person, but it was very good."

"Much more reassuring waiting at home for two hours than in the hospital."

"This way we could avoid unnecessary travel and save time. And if the doctor deems it

necessary to see us, he would give us an appointment by phone.”

“I had my follow-up with my specialist via Zoom, very helpful.”

“I had no choice, it was better than being left with no information.”

“I was in telephone contact at the end of the follow-up with my radio oncologist in Longueuil... and it was perfect!”

However, consultations are still often done by telephone, which is not always appreciated, as patients prefer videoconferences:

“Very satisfied with my videoconference meeting and disappointed with the telephone meeting.”

“Phone only. Would prefer video conferencing.”

“Less spontaneity on the phone.”

Some people indicated a strong preference for face-to-face consultations:

“Some appointments are over the phone rather than in person. I've just been diagnosed, I prefer in person...”

“We should have more follow-ups and especially videoconferences to see our doctor, to show our emotions and the places that hurt us.”

“Received 2 calls from the doctor, explanations are given quickly, I miss being there in person because we can ask more questions.”

“I find it very difficult to talk to doctors, nurses and pharmacists over the phone.”

“I was operated on February 24, 2020, and the follow-up appointments with the surgical oncologist and gynecologist had to be done by phone (I'm in Abitibi and was operated on at the CHUM). I would have liked to see them in person for this first meeting...”

“I don't see my doctors anymore. I no longer see my pivot nurse. My interactions are only by e-mail or phone. This is not the comprehensive approach to health care that we're entitled to.”

“It's better than no date at all. But for me, what I need is to see my medical specialist in person. Because what I need most is reassurance about my current situation and what's coming.”

“I'm visual and I like to see the eyes and the reaction of the people I'm talking to.”

“I wish I could have seen my doctor.”

“I would still prefer to have physical contact with my oncologist.”

“We can no longer look at the results together. I get much less time and less information out of these meetings.”

Or that this type of relationship is not optimal:

"It's hard to assess physical pain over the phone..."

"The tele-consultation lasted a very short time and I didn't get to ask any questions."

"They're very expeditious. They don't take the time to explain anything to me, and the treatment plan has been decided for me; no options have been presented to me."

"It's fast, impersonal, unsettling... some news freezes us and there's no time to organize our thinking to ask clarifying questions."

"I can't get to my doctors. Our communication is unplanned. I receive a phone call from a 'stranger' while I am tele-working, which is difficult enough. I would like a planned contact so that I can be ready and attentive."

"I don't feel like I'm being heard and that decisions are being made in advance."

"I was informed by a health care professional on April 27th by phone that I had cancer, but that he could not tell me more. It is very upsetting to know that I have cancer, but not to know during the 3 days at what stage of cancer I am."

"It's not pleasant to learn that I'm going to die and there's nothing you can do to cure me over the phone. I won't make it to my 50th birthday and I found that out over the phone."

It all depends on the professional:

"It depends on the specialist I've talked to. It worked well with my medical oncologist, my dermatologist and my allergist, but not as well with my surgical oncologist. It was all done by phone."

Access to Medicines

In general, there do not appear to be any deferred drug shortages, but respondents shared varying situations depending on access to drugs:

"However, drugs are rationed. I used to buy my drugs every 3 months and now I have to buy every month. I am concerned about this."

"The pharmacist limited my medication to a 4-week supply instead of 8 weeks, but I can still get everything."

"Ibrance's renewal has been a problem with my insurance twice."

"The prescription never arrived from my doctor at my pharmacy over the Easter weekend. As a result, I started taking cancer medication a week late."

"I had to take Tamoxifen, but it was generic."

6. DATA COMPARISON BETWEEN APRIL AND MAY 2020 CONSULTATIONS

At the beginning of April, the first survey was distributed to oncology patients to evaluate the impact of the measures put in place to counter the COVID-19 pandemic while we were still in the early stages of the health crisis. Six weeks later, a second survey (this one) was conducted to observe the progression of the patients' situation over the last few weeks. The two questionnaires used to conduct these surveys have common questions. In this section, we will compare the results obtained in order to highlight areas of improvement and to identify areas that need to be considered.

Note that the number of respondents to the May survey is slightly lower, with 592 and 402 respondents, respectively. This decrease (32% fewer respondents) can be attributed to the fact that many surveys regarding the impacts of the pandemic situation emerged since the first one we conducted, and that this second survey had three times as many questions as the first.

Comparison of Respondents

1) NUMBER

Note that the number of respondents to the May survey is slightly lower, with 592 and 402 respondents respectively. This decrease (32% fewer respondents) can be attributed to the fact that many surveys regarding the impacts of the pandemic situation emerged from the first one we conducted, that this second survey had three times as many questions as the first, and finally, that we applied different exclusion criteria that we didn't have in the first survey.

2) GEOGRAPHICAL ORIGIN OF RESPONDENTS

It is relevant to note the following variations, given that the picture of the health crisis varies greatly from one region to another. Montreal, for example, has become a major pandemic hotspot not only for the province, but also for the country as a whole. It would be surprising if this did not have an impact on the results obtained.

An analysis of the distribution of participants by administrative region shows that a higher proportion of individuals responding to the second survey came from Montreal. Indeed, in the April survey, 22.8% of respondents were from Montreal compared to 33.1% in the May survey.

There was an increase in the number of people from the Chaudière-Appalaches region, from 4.6% to 9.5% between the two surveys.

The proportion of respondents from the Montérégie and Capitale-Nationale regions

decreased in the second survey. We note that the proportion of respondents from Montérégie decreased by 3.7% (20.5% to 16.8%), while the proportion of participants from the Capitale-Nationale decreased by 8.4% (17.1% to 8.7%). However, these regions remain among the most represented.

The distribution of participants changed little in most of the other administrative regions. It should be noted that there were no participants from Northern Quebec, Nunavik and James Bay Cree Lands. These territories are often under-represented in the public consultations, despite the fact that their populations experience particular issues related to regions far from major urban centres, access to health care and social services, and the social determinants of health. We hope that governments actively survey these populations in the development of their public health policies.

3) TYPE OF CANCER

Breast cancer remains the most common type of cancer in both surveys. However, the proportion of people with this type of cancer decreased from one survey to the next, from 76.2% to 58.0%.

This variation may be due to the greater mobilization of different associations related to more varied forms of cancer. They contributed to a wider dissemination of the survey, through various distribution channels, which allowed an increase in the representativeness of other forms of cancer such as those of the urinary system and lung.

In the first survey, only 1.2% of participants had urinary tract cancers. This time, they represented 10.2% of respondents (prostate cancer 8.5% and bladder cancer 1.7%).

Those followed for lung cancer were about twice as represented in the last survey, the proportion having risen from 2.3% to 5.0% of respondents.

4) COVID-19 TEST

In both surveys, the majority of respondents were not tested for COVID-19. There was a small increase in the number of respondents who answered “yes” to the question, from 2.5% to 10.2% between the two surveys. This may be due to the measures taken by the provincial government to increase testing capacity in transmission sites, as well as the greater availability of mobile testing and testing centres for COVID-19.

5) REMOTE CONSULTATION WITH A PROFESSIONAL

The proportion of respondents who had received a remote consultation with a health professional increased significantly in recent weeks (18.8%). In the first survey, 58.6% of respondents said that telemedicine had been offered to them, while 77.4% of respondents used it in the last survey. This result reflects the change in the practice of health professionals in the last month to allow for more effective management of patients with cancer. This second survey also allowed us to confirm patients' satisfaction

with this new practice and their preference for virtual communications that allow for visual exchanges.

6) DIFFICULTY IN ACCESSING PRESCRIBED MEDICATION OR TREATMENTS

When asked about the difficulty in accessing certain drugs or treatments, participants responded similarly in both questionnaires. In both cases, the vast majority of participants indicated that they were not too bothered by such access difficulties. Only 6.8% and 8.7% of the participants in the first and second surveys said they had been inconvenienced. Those who had encountered this problem were asked to provide the name of the medication or treatment they had been unable to obtain. Herceptin® injectable solution was the only one mentioned in both surveys.

7) TYPE OF ONCOLOGY DRUG PRESCRIBED

The proportion of participants taking oral tablets is fairly close between the two surveys, going from 57.4% to 51.3%. The number of respondents taking intravenous or subcutaneous medication increased somewhat based on the survey results presented above.

8) IMPACT ON ONCOLOGY PATIENTS FOLLOWING COVID-19 PANDEMIC MEASURES

The context of the COVID-19 pandemic was a source of anxiety for most participants in both surveys. Last April, 66.7% of respondents said that the pandemic was contributing to the increased psychological impact of the disease. The latest survey shows a slightly lower rate of 65.0%. Although several measures have been put in place to reduce uncertainty at the time of this health crisis, the fact remains that a majority of patients treated for cancer are still more anxious than usual.

7. MAIN FINDINGS

[Status of the recommendations presented in the previous report](#)

Following the first report, and the challenges and impacts on oncology patients, 15 recommendations were made (table in appendix). 73% of them have been partially or completely implemented, and some are still in progress. This shows that the current government is open to listening to groups like ours and takes into account the problems experienced by people affected by cancer and their loved ones.

1) UNDERSTANDING THE REALITY OF THE PEOPLE AFFECTED BY CANCER

Analysis of the data demonstrates the importance for public policy to consider not only the voices of patients in active treatment, but also those living after an episode of cancer (survivors or people in remission) and their caregivers.

Following cancer treatment, people continue to require support and follow-up. They often live with increased anxiety, a weakened immune system, and face physical, emotional, and social side-effects. It is important to remind them that they can turn to the health care system at any time, especially to their primary care team.

Caregivers are also valuable sources of information and support, especially in cases of advanced cancer. It is therefore important to take into consideration what they are going through and to provide them with the required support.

2) IMPACT OF THE PANDEMIC ON VULNERABLE POPULATIONS, INCLUDING THOSE AFFECTED BY CANCER

This survey also highlights that despite several measures implemented since March, the anxiety level of people affected by cancer remains higher than usual during this health crisis, and stable in its proportion of people affected since April (67% and 65% respectively). However, based on evidence from the qualitative analysis and the questions measuring psychological impact, the degree of distress appears to be lower compared to the first survey. Anxiety, worry and despair were only persistent among 10 to 20% of respondents.

However, the effect of the pandemic on feelings of isolation and sleep disturbances appears to be more pronounced (30%). The numerous testimonials still indicate a great need for psychological support, not only in times of crisis, but also as an integral part of the services offered by the healthcare system.

Although access to care has improved over the past month, concerns about **access to specialists, the risk of jeopardizing one's vital prognosis due to additional delays, the fear of contracting COVID-19, or the isolation that prevents them from receiving help from their loved ones** continue to persist among respondents.

3) TRUST IN THE SYSTEM AND IN GOVERNMENT

In general, respondents **were satisfied with the government's response to the pandemic**. Only one quarter of respondents responding that they were dissatisfied or very dissatisfied. In addition, cancer patients' confidence in the health care system was high, with an average of almost 8 out of 10 (10 = full confidence).

8. RECOMMENDATIONS

Most of our recommendations address the reality of cities or regions that have been affected by the pandemic. They were developed based on patient needs and then discussed with experts to validate their relevance and feasibility.

Three types of recommendations are proposed:



RENEWED - Recommendations from the previous report are being reiterated and renewed since they have not yet been implemented but are still relevant as a result of the responses to this survey.



NEW - New recommendations are proposed in relation to certain concerns that were not assessed in the first survey.



LESSONS LEARNED - Lastly, important recommendations are linked to the lessons learned from this crisis in order to be proactive and be better equipped to cope with a possible second wave following deconfinement.

They address five main themes for which 18 recommendations are made:

1. Continuum of care and services

- Continuity of care and access waits
- Tele-medicine
- Travel

2. Protection of immuno-compromised persons

- Access to mental health care and services
- COVID-19 screening tests
- The use of community resources

3. Caregivers, patient-partners or patient-supporters

- Their presence
- The announcement of the diagnosis
- Their involvement
- Their role in the significant impact of social isolation

4. Information

- The Quebec Cancer Registry
- Consultation with key stakeholders

5. The fragility of the system

- Risks of system overload
- Risks of lack of equipment

1. CONTINUUM OF CARE AND SERVICES

CONTINUITY OF CARE AND ACCESS DELAYS

73% of respondents still feel that the pandemic has affected or will affect their care planning. 50% expressed concern that emergency measures are affecting or will affect the continuity of their care. 50% of respondents are still experiencing rescheduling of appointments (surgeries, imaging tests, screening tests, diagnostic tests, research protocol, specialist follow-up). Most activities resumed in May or June, but waiting lists are getting longer as a result of several months of suspension of activities.

RECOMMENDATION 1. Develop a specific plan to restart oncology activities and manage waiting lists that will reassure people waiting for care or services that they will receive them in a timely manner that does not compromise their vital prognosis.



TELEPHONE AND TELEMEDICINE

The survey confirmed that the population is not only ready to adopt telemedicine consultations, but that there is widespread support for its use. 77% of respondents were already using it, and 72.7% said they were satisfied or very satisfied. On the other hand, a large majority of the comments indicate that patients prefer video consultation whenever possible, as they miss the more human and the non-verbal aspects of in-person appointments. However, given the receptiveness of patients to this technology, it would be desirable to encourage its retention for people living in remote regions to facilitate their access to health professionals (including specialists). Clinical professionals consulted by the Quebec Cancer Coalition in preparation for the survey also agree. For certain specialties (e.g., dermatology) the telephone remains insufficient to replace an in-person consultation. Currently, there is still an issue of high-speed Internet access being quite uneven in Quebec. Therefore, the current government's election promise to invest \$400 million dollars over four years to provide high-speed Internet connection and broadband cellular coverage over 100% of Quebec's inhabited territory.⁵⁻⁶ is more relevant than ever.

RECOMMENDATION 2. During the pandemic, systematically prioritize telemedicine follow-up calls and prioritize methods that allow patients to see the person who reaches them. The telephone should only be used when Internet use is not possible. It is necessary to guarantee health professionals access to a secure and free platform. Deploy the infrastructure to enable the use of telemedicine, including



⁵ <https://coalitionavenirquebec.org/en/blog/2018/08/31/caq-promises-high-speed-internet-everywhere/>

⁶ <https://montrealgazette.com/news/quebec-election-caq-pledges-400m-for-province-wide-internet-cell-access>

videoconferencing, in oncology, specialized and primary care.

TRAVEL TO ACCESS HEALTH CARE SERVICES

56% of respondents who needed access to surgery, treatment or research protocols were willing to travel outside their administrative region to access them more quickly in areas less affected by the pandemic. This willingness to travel up to 200 km or more is strongly correlated to the severity of the prognosis. As a result, patients with advanced cancers are even more willing to travel anywhere in Quebec than stage 1 or 2 patients. In cases where waiting times could be potentially life threatening, it might be desirable for patients to be referred by their physician to another facility while preserving the responsibility of the referring physician, and/or that incentives be put in place to ensure timely access that is optimal for the patient's well-being.

RECOMMENDATION 3. Allow patients on a waiting list in their institution to choose to speed up the process by having the option of accessing another institution - which can ensure their safety, the safety of the health care providers and continuity of care - while maintaining the connection with the local clinical team that will provide follow-up.



2. PROTECTION OF IMMUNOCOMPROMISED PERSONS

PSYCHOLOGICAL DISTRESS AND ACCESS TO MENTAL HEALTH CARE AND SERVICES

More than 65% of those affected say that the pandemic has worsened their existing anxiety or mental health problems. In their testimonies, many people said that they are experiencing psychological effects without having had access to appropriate resources. The lack of integration of mental health into physical health care and services is not new. On the other hand, this crisis highlights these shortcomings and creates an opportunity for improvement.

RECOMMENDATION 4. Conduct systematic screening and regular reassessment of psychological distress in oncology and establish response services that are accessible within a timeframe that corresponds to the person's level of distress.



TESTING FOR COVID-19

Despite some guidelines that allow cancer patients to be tested for COVID-19, very few patients report having been tested (2% in May, 8.5% in June). However, patients confirm that one of their

greatest concerns during this pandemic is the fear of contracting the virus for themselves or their caregivers. Several patient organizations are calling for patients and their families to have access to screening for COVID-19, regardless of whether they are symptomatic or not, especially in preparation for a hospital visit.

RECOMMENDATION 5. Ensure access to COVID-19 screening tests for oncology patients and their families, as well as for health care workers in the network (including home care).



USING COMMUNITY RESOURCES IN THE HEALTH SYSTEM

In April, patients often expressed anxiety about hospital visits and fear of contracting the SARS-CoV-2 virus. However, other structures in the health system could have been mobilized if the right preparation had been in place. We are referring for example to community pharmacies, community clinics (CLSCs), and home care teams from the public network or those from community organizations⁷, which could be called upon and mobilized to carry out certain tasks (blood tests, monitoring vital signs, administering medication, etc.). This would make it possible to reduce the risks of contagion for patients and the community. In the event that this recommendation is adopted, it would be important to ensure that personnel are dedicated to these populations and are in no way assigned to potentially hot zones.⁸

In the same vein, INESSS has made several recommendations to adapt cancer treatments and to favour certain treatments that may be as effective and may *reduce hospital visits*.⁹ These include the use of oral rather than intravenous drugs, or the use of precision drugs as first line treatment, for patients who would benefit from them now rather than in the third line. These decisions would not only improve patient well-being, but also minimize the use of health system resources (e.g., fewer hospitalizations and face-to-face hospital visits).

RECOMMENDATION 6. Plan for increased use of **CLSCs, home care and community pharmacies** for the care and services to be offered to people affected by cancer. In the event of a second wave of the pandemic, support these resources and ensure that they have all the protective equipment and hygiene measures in place to protect their staff, patients and their loved ones, in order to better relieve the hospital system.



RECOMMENDATION 7. Encourage the prescription of treatments and medications that can reduce hospital visits, and thus the risk of contagion, while providing health results equivalent or superior to usual treatments. (e.g., oral medication or precision treatments).



⁷ For example, [NOVA Montréal](#).

⁸ A, Picard. In the stay-at-home era, why have we so sorely neglected home care? 15-06-2020.

<https://www.theglobeandmail.com/opinion/article-in-the-stay-at-home-era-why-have-we-so-sorely-neglected-home-care/>

⁹ <https://www.inesss.qc.ca/covid-19/cancerologie.html>

CAREGIVERS, PATIENT-PARTNERS OR PATIENT-SUPPORTERS¹⁰

PRESENCE OF CAREGIVERS DURING CONSULTATIONS

Patients have complained that they have not been able to benefit from the support of their family caregivers during their consultations or treatments, leading to a great deal of anxiety and insecurity. The challenge is even greater with people of immigrant background, who are older, or who are highly dependent on their caregivers. A recommendation similar to the one issued by the INESSS on April 17, on “socialization at a distance: residents and caregivers” could have a very beneficial impact in reassuring patients and ensuring that the right information is transmitted.

RECOMMENDATION 8. **Develop a policy for the presence of family caregivers during medical consultations,** to encourage their participation in person or via telemedicine, when the person facing a cancer problem wishes to do so.



THE PRESENCE OF RELATIVES WHEN THE DIAGNOSIS IS ANNOUNCED

In the comments collected, situations of great concern were reported in connection with the announcement of the diagnosis by telephone. This practice is obviously to be avoided. The announcement of the diagnosis must be made in the presence of another person, a relative if possible, or with a patient-partner-supporter.

RECOMMENDATION 9. Make all diagnostic announcements face-to-face whenever possible (not over the telephone); ensure that all announcements are made in the presence of a family member or **patient-partner-supporter**.



INVOLVEMENT OF FAMILY CAREGIVERS

Consistent with the upcoming new law on caregivers (Bill 56 on caregivers¹¹, to recognize and support family caregivers) this survey reflects the need for caregivers to be considered. Restricting their presence can have deleterious effects on patients, many examples of which have been reported in the media. Thérèse Martineau's is probably the best known ¹²⁻¹³. While

¹⁰ A patient partner is a patient who wishes to mobilize his or her experiential knowledge for other patients. Supporting patients mobilize their experiential knowledge for other patients at the clinical level by accompanying them in their care trajectory. (<https://chaireengagementpatient.openum.ca/projets-de-recherche/parole-onco-2/>).

¹¹ <https://www.lapresse.ca/actualites/politique/2020-06-11/quebec-depose-son-projet-de-loi-pour-une-politique-nationale-des-proches-aidants>

¹² T. Gerbet. (4 mai 2020) L'amour d'un fils face aux directives du gouvernement. *La Presse*. <https://ici.radio-canada.ca/nouvelle/1699718/mere-chsld-visite-humanitaire-residence-proche-aidant-covid>

¹³ F. Pelletier. (6 mai 2020) La solitude tue. *Le Devoir*. <https://www.ledevoir.com/opinion/chroniques/578336/la-solitude-tue>

the presence of relatives is important for patients with COVID, it is equally important for those with cancer. However, many solutions can be contemplated to allow the presence of relatives. The work of an international Coalition on the issue of informal caregivers during a pandemic has led to the identification of eight recommendations¹⁴ in this regard. The Centre of Excellence on Partnership with Patients and the Public (CEPPP) also issued recommendations on the subject.¹⁵ It therefore seems to us that it is very important for oncology patients to engage with family and friends, in a spirit of partnership and teamwork, to ensure the quality and security of their care. Relatives should therefore be considered as part of the solution for the health network and trained accordingly.

RECOMMENDATION 10. Encourage the presence of caregivers in a spirit of partnership and ensure their safety, that of patients and staff, by setting up mandatory **training** for family carers on **hygiene rules and the use of personal protective equipment (PPE)**.



SIGNIFICANT IMPACT OF SOCIAL ISOLATION

Both surveys highlighted the effects of social isolation on mental health. At the onset of the crisis, patients who had cancelled appointments, treatments or surgeries sometimes found out about them from answering machines. Patients had a great need to be reassured and to maintain contact with their treatment team. In this second survey, patients reiterated this need.

67% of respondents had been in contact with their treating team and stressed the importance of contact with people who reassure them. Care teams have the ability to observe the state and fluctuation of patients' psychological health. As for oncology patients, their level of distress is poorly documented, they are not well equipped to deal with it, and there are not enough resources to ensure that they have the access to them when they need it. Because they often do not dare to talk about anything that isn't directly related to cancer, patients often hesitate or wait a long time before expressing their psychological needs. When they finally do come forward, their issue may have worsened and the wait times are often far too long for the level of distress they experience.

RECOMMENDATION 11. Ensure regular follow-up (every 2-3 weeks) of patients followed by cancer services by trained individuals (e.g., nurse, social worker, or **patient-partner-supporters**); these individuals could contact patients who are not being actively followed to inquire about their needs, and make sure to relay the information to the treatment team.



¹⁴ [Lignes directrices centrées sur la personne pour maintenir la présence des proches durant des périodes difficiles.](#)

¹⁵ Centre of Excellence on Partnering with Patients and the Public. (2020, March). Discussion Paper: Recommandations CHUM pour les patients COVID-19 isolés et sur le partenariat patient. Centre hospitalier de l'Université de Montréal, Montreal, QC, Canada.

INFORMATION

CANCER REGISTRY

Each day, the number of cases of people infected, the number of deaths, and the number of people cured of COVID-19 are published. Real-time data on people affected by cancer should also be available through the Quebec Cancer Registry established in 2008. However, according to the Quebec Oncology Registrars Association, the most complete data currently available is from 2012-2013. One may therefore wonder why data on SARS-Cov2 infection can be produced in real time, yet in oncology, the data is 8 years old.

In the previous report, we highlighted the importance of being able to monitor the incidence of cancer cases, its mortality, remission rates as well as excess mortality in Quebec on a daily basis. Thanks to Artificial Intelligence (AI), it should be possible to extract information from the local registries of institutions that are up to date, information that can be fed into a Quebec Cancer Registry. This data could be used by policy makers and researchers to inform public policy that has an important impact on the lives of people affected by cancer. Without such monitoring, it is difficult to measure the real impact of the pandemic, whether on screening programs, different types of treatments, delays in diagnosis or access to experimental protocols.

RECOMMENDATION 12. Update the mission of the Quebec Cancer Registry, whose objective is to allow monitoring of the situation in relation to people affected by cancer in order to have in real time: incidence, mortality rate, excess mortality rate (medium and long term), care trajectories, and remission rate in the Quebec population. Use Quebec's AI expertise to ensure reliable data in (near) real time.



THE QUEBEC CANCER PROGRAM'S DECISION-MAKING PROCESS

The management of the COVID-19 crisis led to the observation that few stakeholders were consulted, starting with patients. The National committee for people affected by cancer and the cancer coordinating committees of each establishment, which support the management of the Quebec Cancer Program / Programme québécois de cancérologie (PQC)¹⁶ at the Quebec Health Care Ministry, were barely consulted. However, there are also various other patient-partner bodies, such as the COVID-19 Citoyens Partenaires (C4P) Advisory Committee or the CRCHUS¹⁷ Patients-Partners Strategic Committee (to name but a few), which have experience in this type of consultation and are able to provide guidance to decision-makers. For example, the CEPPP's experience in creating the COVID-19 Citoyens Partenaires (C4P) Advisory Committee, which was

¹⁶ [Programme québécois de cancérologie.](#)

¹⁷ 2019 Cancer Award from the Programme québécois de cancérologie. Category Involvement of people affected by cancer. Project: The Patient-Partner Strategic Committee of the CHUS Research Centre: two years of patient achievements in oncology. <https://www.msss.gouv.qc.ca/ministere/lutte-contre-le-cancer/congres-2019/#prix>

involved with the COVID-19 Ethics Committee of the Health Care Ministry has made it possible to issue recommendations that are much more in line with the reality on the ground, while taking into consideration the human dimension, particularly with regard to levels of care and emergency room triage. The inclusion of patient-partners in this exercise is another example. Their presence, as in most initiatives that genuinely engage patients in the co-construction of solutions, brings perspective and new insights for reflection that contribute to the recommendations that are being proposed. Moreover, we note that patients have often anticipated the problems that will arise. It would therefore be desirable, especially in view of a second wave of the pandemic, that the people concerned be consulted and be part of the search for solutions. The acceptability of such solutions would also be enhanced with their involvement.

RECOMMENDATION 13. Implement consultation mechanisms, **upstream of the decisions to be made**, with known groups (strategic, clinical, research) that bring together patient-partners in oncology to ensure that the concerns of a variety of patient-partners is as representative as possible and is taken into consideration.



THE FRAGILITY OF THE SYSTEM

The health crisis in Quebec began with a narrow focus on protecting the hospital system. Long-term care facilities (CHSLDs), community clinics (CLSCs), home care, cancer care, clinical studies and community pharmacies are also part of the continuum of patient care and require attention proportional to the attention given to hospitals. In the event of a second wave of the COVID-19 pandemic this fall, **we believe that by being proactive and learning from this experience, it is possible to anticipate possible negative consequences and ensure optimal protection of the most vulnerable people - including oncology patients.**

LACK OF ESSENTIAL EQUIPMENT TO COUNTER COVID-19

In During the first wave, health facilities had to cope with the scarcity of personal protective equipment (PPE), disinfectants, ventilators, and sometimes analgesic drugs. Better planning is therefore needed to be better prepared for a resurgence of the pandemic situation.

RECOMMENDATION 14. Plan now for an adequate supply of PPE, disinfectants, ventilators and analgesic medications for the **entire health network** (including CLSCs, home care, clinical research centres, and community pharmacies) for the next 12 months.



HOSPITAL OVERLOAD

The measures put in place in March 2020 to minimize essential activities have helped protect the hospital system from overload. However, what will happen in the fall, if hospital emergency departments find themselves struggling not only with a resurgence of COVID-19 cases, but also

with the usual cases of influenza and pneumonia that are already creating some crowding in hospitals? It would be important to reduce the risk of having to deal with several viruses at the same time, especially since the symptoms are similar and will be difficult to distinguish. It will therefore be essential to avoid having all these people appear at the same time in the emergency room, monopolizing hospital resources and repeating the April emergency scenario, which led to the closure or slowing down of oncology services. Winter clinics¹⁸, which normally run from December to March, as well as the screening clinics for COVID-19 are a great model for sorting out symptoms outside of hospitals.

Each year in Canada, 135,000 emergency department visits are related to pneumonia¹⁹, with an average stay of 11.5 days²⁰. For seasonal influenza, there have already been 54,000 cases of influenza detected since November 1, 2020 and 3,500 Canadians die annually²¹. Knowing that there are vaccines to prevent community-acquired pneumonia (CAP) and influenza, which are currently covered by the public health plan for seniors and vulnerable populations, it would be beneficial - for the population and the Quebec health system - to increase the vaccination rate not only for these people, but also for essential workers and health professionals. In addition, with the reopening of schools and greater deconfinement planned for September, it would be proactive to vaccinate the entire population, if possible. The government is potentially considering advancing the annual vaccination campaign²², which would allow for better control of the spread of these viruses. In addition, the new powers of community pharmacists - permitted under Bill 31²³ - which strengthen the front line, should also be used to help relieve the strain on the health care system.

RECOMMENDATION 15. **Promote and offer free of charge (as currently proposed for seniors and vulnerable populations) the influenza and pneumococcal vaccine to all Quebec citizens, while waiting for a COVID-19 vaccine, in order to limit the number of hospitalizations as much as possible. If it is not possible to publicly cover vaccines for the entire population, increase the vaccination rate among seniors and immunocompromised people as well as health care workers and promote voluntary vaccination through a targeted awareness campaign.**



¹⁸ <https://www.quebec.ca/en/health/health-system-and-services/service-organization/winter-clinic/>

¹⁹ Canadian Institute for Health Information. Pneumonia a leading cause of emergency department visits in Canada last year. 2018. Accessible at <https://www.cihi.ca/en/pneumonia-a-leading-cause-of-emergency-department-visits-in-canada-last-year>. Consulted on June 20, 2020.

²⁰ LeBlanc JJ et al. *Burden of vaccine-preventable pneumococcal disease in hospitalized adults: A Canadian Immunization Research Network (CIRN) Serious Outcomes Surveillance (SOS) network study.* Vaccine. June 22, 2017;35(29):3647-54.

²¹ Radio-Canada Published January 29, 2020 | Updated April 2, 2020. <https://ici.radio-canada.ca/nouvelle/1493696/coronavirus-influenza-mortalite-canada-virus-epidemie-grippe>. Consulté le 20 juin 2020.

²² R. Schué Radio-Canada. Published on June 18, 2020 <https://ici.radio-canada.ca/nouvelle/1712905/covid-grippe-vaccin-quebec-sante-canada-sanofi>. Consulted on June 20, 2020.

²³ Bill 31, An Act to amend mainly the Pharmacy Act to facilitate access to certain services. Assented to 17 March 2020. <http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=5&file=2020C4A.PDF>

RECOMMENDATION 16. **Include community pharmacies in the public immunization campaign against influenza and pneumonia** by collaborating as of now in providing services to the population and ensuring that they are provided with the necessary PPE and clear guidelines for hygiene and distancing measures, so that vaccines can be administered in pharmacies efficiently and safely.



RECOMMENDATION 17. Triage potential cases of influenza, pneumonia, and COVID-19 in dedicated clinics outside the hospital.



Similarly, certain places other than hospitals have the equipment and can offer intravenous treatment to cancer patients (for example, private infusion centres that are already conducting clinical studies, or participating in patient support programs). They have the expertise, the excess capacity, the safeguards in place, and they are not risk areas for immunocompromised patients. The circulars (ministerial directives) that govern these activities could be amended to change the rules. In a second wave context, these centres could free up hospitals by administering certain treatments themselves, under the responsibility and supervision of the public health network, while ensuring greater control of the risks of contagion for oncology patients.

RECOMMENDATION 18. **Allow intravenous treatment outside of hospitals**, for example in infusion centres, at home, or in other health care facilities.



ANNEX

Annex 1: Survey Questionnaire



Survey on the Impact of COVID-19 Pandemic's Response Measures on Oncology Patients in
Quebec - May 2020

The Quebec Cancer Coalition is aware of the exceptional nature of the COVID-19 global crisis and is solidary with the collective efforts needed to counter the pandemic. It is consulting you in a spirit of honest collaboration with Quebec's Health and Social Services Network.

The Quebec Cancer Coalition would like to know oncology patients' opinion regarding government's measures put in place to counter the COVID-19 pandemic, the issues resulting from these measures and the impacts on patients, 10 weeks into their implementation.

For this survey, the Quebec Cancer Coalition is looking for participants who have cancer or are still undergoing regular medical follow-ups (or their family caregiver completing the survey on their behalf), in order to better understand their situation in the context of COVID-19.

Your experience and testimony will allow us to identify current problems and to intervene according to your needs, in order to recommend solutions to the Quebec Ministry of Health and Social Services, that are realistic and coherent with the current situation.

Your participation in this survey contributes to improving health care and social services for all Quebecers.

* 1. You are:

- | | |
|---|---|
| <input type="checkbox"/> A person waiting for a screening test | <input type="checkbox"/> A patient in remission |
| <input type="checkbox"/> A person waiting for a diagnostic result | <input type="checkbox"/> A family caregiver of a patient who is responding on behalf of a patient (please check the appropriate boxes for the patient in this and subsequent questions) |
| <input type="checkbox"/> A patient in active treatment | <input type="checkbox"/> None of the above |
| <input type="checkbox"/> A patient awaiting treatment/surgery | |



Survey on the Impact of COVID-19 Pandemic's Response Measures on Oncology Patients in
Quebec - May 2020



*** 2. What is your current situation?**

- | | |
|--|--|
| <input type="checkbox"/> I need to get tested, but I don't have any signs of cancer | <input type="checkbox"/> My cancer treatments have been postponed until an undetermined date |
| <input type="checkbox"/> I have a possible sign of cancer and I need to get tested | <input type="checkbox"/> I'm awaiting surgery |
| <input type="checkbox"/> I've been tested for cancer and I'm waiting for the results | <input type="checkbox"/> My treatments have been postponed to a specific date |
| <input type="checkbox"/> I'm waiting to take an imaging test | <input type="checkbox"/> I am participating in a clinical trial/research protocol |
| <input type="checkbox"/> I've been diagnosed with cancer and I don't have a start date for treatment | <input type="checkbox"/> I am awaiting participation in a clinical trial/research protocol |
| <input type="checkbox"/> I have been diagnosed with cancer; I will be receiving treatment according to a modified plan during the pandemic | <input type="checkbox"/> I'm already in treatment and the pandemic hasn't affected my treatment plan |
| <input type="checkbox"/> I have been diagnosed with cancer; I will be receiving treatment, according to an unchanged plan | |
| <input type="checkbox"/> Other (please specify): | |

*** 3. What type of cancer do you have or have you had (initial location)?**

- | | |
|--|--------------------------------|
| <input type="radio"/> Lung | <input type="radio"/> Ovarian |
| <input type="radio"/> Colorectal | <input type="radio"/> Bladder |
| <input type="radio"/> Breast | <input type="radio"/> Lymphoma |
| <input type="radio"/> Prostate | <input type="radio"/> Myeloma |
| <input type="radio"/> Other type of cancer (please specify): | |

*** 4. Stage:**

- | | |
|-------------------------|------------------------------------|
| <input type="radio"/> 1 | <input type="radio"/> 4 |
| <input type="radio"/> 2 | <input type="radio"/> I don't know |
| <input type="radio"/> 3 | |

*** 5. Have you been tested for COVID-19?**

- ☐ Yes
- ☐ No
- ☐ Not applicable

Comments



* 6. What are your current needs? You may check more than one option.

- | | |
|--|--|
| <input type="checkbox"/> Take a screening test | <input type="checkbox"/> Securing additional financial resources |
| <input type="checkbox"/> See or talk to the specialists who normally see me | <input type="checkbox"/> Receive information on the impact of the situation on my health (prognosis) |
| <input type="checkbox"/> Be reassured | <input type="checkbox"/> Having some respite |
| <input type="checkbox"/> To have a specific date to start or to resume my treatments | <input type="checkbox"/> Talking to other people in the same situation as me |
| <input type="checkbox"/> To see my loved ones or to feel close to them | <input type="checkbox"/> None of the above |

Other (please specify):

* 7. In the past four (4) weeks, have you had a rescheduled or cancelled appointment for (you may check more than one option):

- | | |
|--|---|
| <input type="checkbox"/> A treatment | <input type="checkbox"/> A follow-up with your doctor |
| <input type="checkbox"/> A diagnostic test | <input type="checkbox"/> A clinical study (research protocol) |
| <input type="checkbox"/> An imaging test (e.g. MRI, ultrasound, X-ray, etc.) | <input type="checkbox"/> An appointment to obtain a diagnosis and develop a care plan |
| <input type="checkbox"/> A screening test | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> Surgery | |
| <input type="checkbox"/> Other (please specify): | |

* 8. In the past four (4) weeks, have you been in contact with your clinical/treatment team?

- ☐ Yes
- ☐ No
- ☐ Not applicable

Comment

* 9. In your opinion, has (or will) the continuity of your care and services been (or will be) affected by the measures put in place to address the current pandemic?

- ☐ Yes
- ☐ No
- ☐ Not applicable

Comment

* 10. Since the start of the containment measures, have you received, or been offered, a remote professional consultation? (A professional consultation is an appointment with a general practitioner, medical specialist or other health or social services professional. A remote consultation takes place by telephone, videoconference or any other means that allows you to contact the professional while remaining at home).

- ☐ Yes
- ☐ No
- ☐ Not applicable

Other (please specify)

11. If you answered YES to the previous question, what is your level of satisfaction with your remote consultation?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comment

* 12. In the past ten (10) weeks, have you had any difficulty accessing medication or treatment prescribed by your oncologist?

- ☐ Yes
- ☐ No
- ☐ Not applicable

Comment

13. If you answered YES to the previous question, what medication treatment are you having difficulty obtaining?

* 14. What type of oncology medication are you prescribed?

- ☐ Oral tablet (pill)
- ☐ Biologic ou biosimilair (intravenous)
- ☐ Patches (transdermal)
- ☐ Subcutaneous injection
- ☐ Other (please specify)

* 15. Do you feel that the pandemic is causing you more anxiety than usual, or that it is aggravating existing mental health problems?

- ☐ Yes
- ☐ No

Comment

* 16. For the past two weeks, my family caregivers can continue to be physically present with me:

- ☐ Yes
- ☐ No
- ☐ Doesn't apply
- ☐ Other (please specify)

* 17. In the past two (2) weeks:

I have found it difficult to focus on anything other than my anxiety...

Never	Rarely	Sometimes	Often	Always
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 18. In the past two (2) weeks:

I have been overwhelmed by my preoccupations...

Never	Rarely	Sometimes	Often	Always
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 19. In the past two (2) weeks:

I have felt desperate...

Never	Rarely	Sometimes	Often	Always
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 20. In the past two (2) weeks:

I have felt isolated from the others...

Never	Rarely	Sometimes	Often	Always
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 21. In the past two (2) weeks:

I have had difficulties falling asleep...

Never	Rarely	Sometimes	Often	Always
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



* 22. Have you experienced any other issues or concerns related to the measures put in place to address the COVID-10 pandemic? You may check more than one option:

- | | |
|--|--|
| <input type="checkbox"/> Fear of being infected with Covid-19 or fear that my loved ones get infected; | <input type="checkbox"/> The loneliness and isolation I experience due to social distancing; |
| <input type="checkbox"/> Fear that the pandemic will affect my health and my prognosis; | <input type="checkbox"/> Managing my family life in isolation; |
| <input type="checkbox"/> Termination of health insurance benefits before having completed all of my treatment needs; | <input type="checkbox"/> The overall impacts of the health crisis on society; |
| <input type="checkbox"/> The end of my employment insurance benefits (15 weeks); | <input type="checkbox"/> None of the above; |
| <input type="checkbox"/> Additional budget pressures caused by the pandemic (e.g. layoffs, lack of job openings, reduced income, additional transportation costs, etc.); | |
| <input type="checkbox"/> Other (please specify): | |

* 23. What services or actions could help me better cope with the pandemic?

- | | |
|--|--|
| <input type="checkbox"/> Regular follow-up updates (by phone or email) with my medical or psychosocial team (contacting me even if there is no change) | <input type="checkbox"/> Extended EI benefits beyond 15 weeks |
| <input type="checkbox"/> Facilitators (special considerations) for people undergoing treatment (e.g. automatic delivery of prescriptions, free masks, etc.). | <input type="checkbox"/> Targeted financial support to community organizations that help me |
| <input type="checkbox"/> General information and support telephone line for cancer patients. | <input type="checkbox"/> Psychological consultations and psychosocial support from professionals |
| <input type="checkbox"/> Having access to a physician through telemedicine (phone or online) | <input type="checkbox"/> Online peer support activities (with other people going through the same thing as me) |
| <input type="checkbox"/> A more complete coverage of my medicine and treatments by public health insurance | <input type="checkbox"/> Online activities to take my mind off things (e.g., physical activity classes, meditation, testimonials, relaxation, etc.). |
| <input type="checkbox"/> Une couverture plus complète de mes médicaments et traitements par l'assurance maladie publique | <input type="checkbox"/> None of the above |

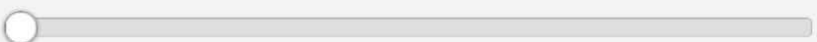
Other (please specify):

* 24. Would you be willing to travel to another region to gain quicker access to surgery or treatment that is not currently available in your usual health care facility because of COVID-19?

- ☐ No ☐ Yes, anywhere in Quebec
- ☐ Yes, but only if it's within a radius of 50 km or less ☐ Yes, anywhere in Canada
- ☐ Yes, but only if it's within a radius of 200 km or less ☐ Not applicable
- ☐ Please specify if your answer applies to surgery, treatment or clinical trial:

* 25. What is your current level of confidence in the cancer health care system's ability to provide you with appropriate care and social services in a timely manner? (1: no confidence => 10: very confident)

1 10



* 26. How satisfied are you with the measures put in place by the Government of Quebec regarding the care of persons affected by cancer?

Very dissatisfied Dissatisfied Neutral Satisfied Very satisfied



* 27. In which region do you live?

28. If you wish, please provide us with your email address so that we can contact you again for the continuation of the survey:

Name

Email

Phone

Annex 2: Recommendations from April 14, 2020 report and updates

Applied recommendations		
SUMMARY OF RECOMMENDATIONS	UPDATES	TO DO - COALITION COMMENTS
Recall that situations other than COVID-19 are also important and are being considered.	Document updated by the INESSS and made public on April 17: "COVID-19 and general considerations concerning the treatment of cancer" and "COVID-19 and immunocompromised persons".	Since April 16, Minister McCann has put efforts in reassuring cancer (and other serious diseases) patients that they are not forgotten and that urgent and non-urgent care will continue.
Conduct regular online surveys to assess the impact and level of psychological distress of people affected by cancer.	A second survey was conducted in early May.	
Set up an INFO-ONCO-COVID line.	The info-cancer lines of the Fondation Québécois du cancer and the Canadian Cancer Society are available to respond to the need, but the government should talk about it during their daily press briefing, because patients complain that they lack information and do not know where to turn.	Minister McCann, could mention and share at a daily press briefing that these onco and COVID support lines exist for people with cancer (as has already been done with other resources for the population).
Establish virtual modalities for delivering wellness services.	Several organizations now offer wellness activities for oncology patients.	
Maintain links between hospitalized persons and their loved ones.	Published on April 17: Socialization at a distance: people living in long-term care facilities and caregivers (French only)	This is an excellent initiative!
Allow at least one family member to be involved in end-of-life care.	Ban lifted on May 5 by the MSSS	

Reorganize services: Give preference to drugs that can be administered at home.	INESSS, April 17: General considerations regarding cancer treatment (French only)	It seems that the guidelines are along the same lines, encouraging drugs that can be administered at home by oral, subcutaneous, or transdermal means, for example.
Reorganize services: Set up a psychological support program.	Published by INESSS on April 17: Effects of the pandemic context on mental health and measures to be put in place to counter these effects . Updated May 6: Enhancement of Info-Social 811 services; improved access to appropriate and timely psychosocial and mental health services for anyone requesting them; intensification of social and psychological counselling services and deployment of priority mental health services, including the enhancement of outreach services.	
Reorganize services: Maintain tele-medicine and continue to deploy it.	INESSS, April 17: General considerations regarding cancer treatment (French only)	Ideally, there should be a clear guideline to ensure continuity of tele-consultation whenever possible, and expand the use of video consultation instead of just over the phone.

Partially applied recommendations		
SUMMARY OF RECOMMENDATIONS	UPDATES	TO DO - COALITION COMMENTS
Encourage professionals to improve their communications with patients.	Document updated by the INESSS and made public on April 17: "COVID-19 and general considerations concerning cancer treatment" states that "the risk/benefit ratio should be discussed with the patient, in order to determine whether it is preferable to start, continue or interrupt treatment in order to avoid contamination by the virus."	The INESSS document is very good, but in the field, these recommendations do not seem to be implemented systematically. Our survey showed a great deal of anxiety related to the lack of information, transparency and lack of partnership with the patient. A more specific mention in directives to institutions, or lines of communication to help clinicians explain changes or delays could greatly reassure patients.
Provide a "post-COVID" recovery plan to monitor wait times for all procedures in the short, medium and long term in a transparent manner.	Firstly, we welcome the reopening of imaging services by Ms. McCann on April 16, which caused a great deal of concern among patients. We know that every effort has been made to reassure the public that urgent and semi-urgent treatments and surgeries are resuming, as well as transplants, radiology, oncology, screening and diagnostics.	There is still no plan to manage waiting lists in a month's time to avoid a real crisis. How can we ensure that surgeries and treatments that can be postponed for 4-6 weeks now will be postponed as long as necessary? With fewer surgeries and other procedures, including diagnostics, what is the plan to avoid delays that will exceed the prescribed time

		and have a negative effect on patient prognosis and mortality?
Monitor shortages of certain drugs and assess the impact of these on patients.	Published on April 17 by INESSS: There seems to be a problem of drug shortages: sedatives, analgesics and neuromuscular blockers; and issues related to palliative care and guidelines to follow.	A risk management plan is still missing to avoid this type of problem.
Reorganize services: Refer surgery to dedicate, non-COVID19 facilities.	Hospitals now have cold, warm and hot zones. Oncology centres are protected from hot zones, and some centres are designated to handle the majority of COVID-19 cases in a region.	We understand that every effort is made to isolate vulnerable patients such as cancer patients in “cold zones.” Whenever possible, would it not be possible to prioritize care or operations in hospitals that are not dedicated to COVID-19? Half of the patients say they are willing to travel for faster access.
Reorganize services : Favour home care.	INESSS, April 17: General considerations regarding cancer treatment (French only)	Home care presents an opportunity to avoid hospital travel. But despite Dr. Arruda

		and Ms. McCann's confirmation that there is no shortage of protective equipment in the system, home care staff are not receiving everything they need to ensure their safety and that of their patients.
Reorganize services: Re-establish research protocols as soon as possible.	On June 5, Assistant Deputy Minister Pierre Lafleur sent a letter to the CEOs of the public institutions allowing the reopening of clinical trials according to the local capacity and situation to control COVID-19.	URGENT. Late stage patients are told that clinical trials will not start for 6 months - they have no time to lose. A plan to reopen oncology clinical trials for patient treatment needs to be put in place.

Recommendations not implemented		
SUMMARY OF RECOMMENDATIONS	UPDATES	TO DO - COALITION COMMENTS
Publish specific mortality rates related to cancer in the short, medium and long term.	Mortality rates due to COVID-19 are known, but not those related to cancer.	Our contacts at the Oncology Registrars confirm that we only have data for 2012. This is an unacceptable delay compared to other provinces. The information is much more up-to-date in local hospital registries. With the expertise in artificial intelligence that we have in Quebec, there is certainly a way to speed up the updating of the Quebec Cancer Registry after a delay of more than 10 years. An in-depth study of the impacts (or not) of the pandemic measures on these patients will undoubtedly be requested after the pandemic, and we lack this data.
Ensure a safety net for patients in serious financial difficulty.	Some patients suffer from financial insecurity and are not eligible for government assistance programs currently available.	Would there be an opportunity to provide assistance at the provincial level?

<p>Promote the participation of family and friends in consultations through tele-medicine.</p>		<p>Patients complain of not having the support of their caregivers during their consultations or treatments, and this causes them a lot of anxiety and insecurity. The challenge is even greater with people of immigrant background or older, who are highly dependent on their caregivers. A directive similar to the one mentioned in recommendation 11 could have a very beneficial impact in reassuring patients and ensuring that the right information is conveyed.</p>
<p>Reorganize services: Carry out intravenous treatment outside of hospitals, for example in infusion centres.</p>		<p>Infusion centres have excess capacity and measures in place to protect patients. They can treat multiple patients effectively in a safe environment. Could a temporary arrangement be put in place during the pandemic?</p>