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FOUNDATION



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sauve ta peau

“The Affects of COVID-19 on Melanoma, Ocular Melanoma, and Non-melanoma Skin Cancer Patients”

A 2020 Patient Survey by Save Your Skin Foundation

Save Your Skin Foundation, May 2020

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INTRODUCTION

From April 9th, 2020— April 27th, 2020, Save Your Skin Foundation ran a patient survey titled “Impact of COVID-19 pandemic on Canadian melanoma, ocular melanoma, and non-melanoma skin cancer patients.” The survey consisted of 21 questions, which ranged between multiple choice, multi-selection, and write-in, and participants had the option to skip any question. The goal of the survey was to assess the impact that the COVID-19 pandemic has had on the medical, social, and financial security of melanoma, non-melanoma skin cancer, and ocular melanoma patients. For the sake of brevity, written answers are not included, and are grouped by topic. The results of the French survey, which was identical to the English survey but directed at French Canadian patients, are summarized after the results of the English survey. For access to the full survey results, contact the Save Your Skin Foundation at taylorkathleen@saveyourskin.ca.

QUESTION 1: “WHO IS ANSWERING THIS QUESTIONNAIRE? IF MORE THAN ONE CHOICE QUALIFIES, PLEASE CHECK THE MOST APPROPRIATE”

The first question in the survey confirmed the demographics of those taking the survey. The majority of participants (84.09%) are currently living with melanoma, ocular melanoma, or non-melanoma skin cancer. 9.09% of the participants are caregivers, while 6.82% categorized themselves as neither a patient or caregiver. Of these participants, 2 are healthcare workers, and 1 is a former melanoma patient.

QUESTION 2: “WHAT PROVINCE ARE YOU A RESIDENT OF?”

The second question clarifies which Canadian province the participants are from. In descending order, 43.18% of participants are from British Columbia; 29.55% from Ontario; 9.09% from Alberta; 4.55% from Manitoba, Nova Scotia, and Saskatchewan individually; and 2.27% of participants each hailed from New Brunswick and Québec. No participants were from Newfoundland and Labrador, Prince Edward Island, or any of the Territories. The measurement given here for Québec does not include the patients who responded to the French language survey, discussed later in this report.

QUESTION 3: “WHAT TYPE OF CANCER DO YOU, OR DID YOU PREVIOUSLY, HAVE? CHECK ALL THAT APPLY”

This question asked what form of melanoma or non-melanoma skin cancer the survey participants either have, or previously had. 66.67% of participants listed melanoma. 22.22% of participants listed Basal Cell Carcinoma, 8.89% ocular melanoma and Squamous Cell Carcinoma separately, and 2.22% Merkel Cell Carcinoma. 11.11% of participants stated that their cancers did not fall into these categories; thyroid, breast, and ovarian cancer were listed here.

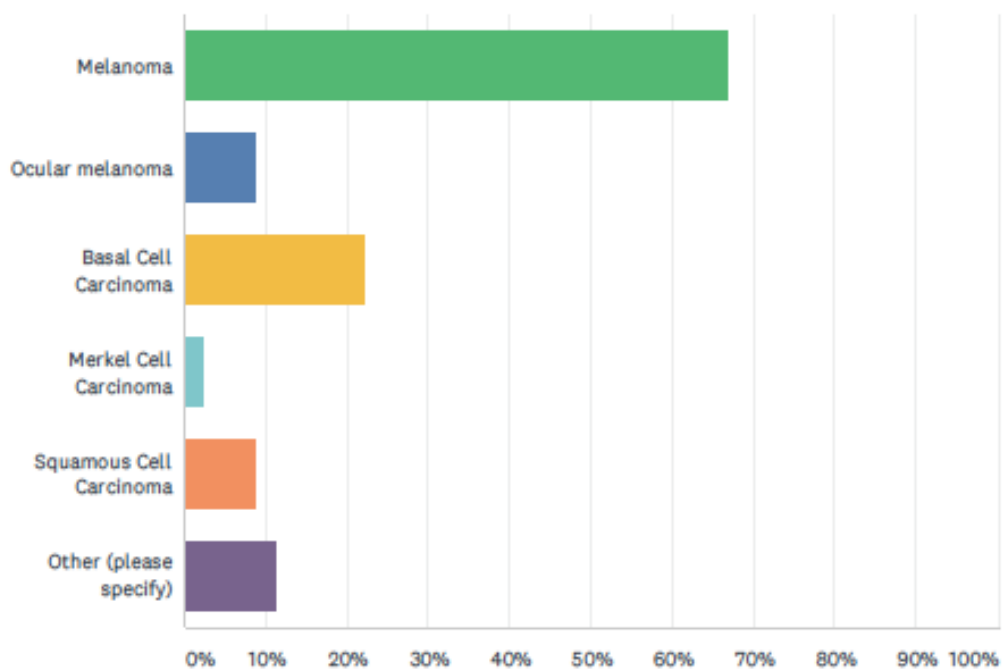


Fig. 1: “What type of cancer do you, or did you previously, have? Check all that apply.”

QUESTION 4: “WHAT BEST DESCRIBES YOUR STAGE OF CARE? CHECK ALL THAT APPLY.”

This question determined where the participants were in the care process at the time they took the survey. The majority of survey participants (51.11%) were in surveillance or follow-up care; 28.89% were in treatment, 17.78% had no evidence of disease; 8.89% were post-surgery; and 2.22% participants were waiting for treatment and waiting for surgery individually. 4.44% of responses were categorized as “other,” 1 of which has had a recent recurrence and is awaiting treatment, and the other 1 found the question was not applicable to them.

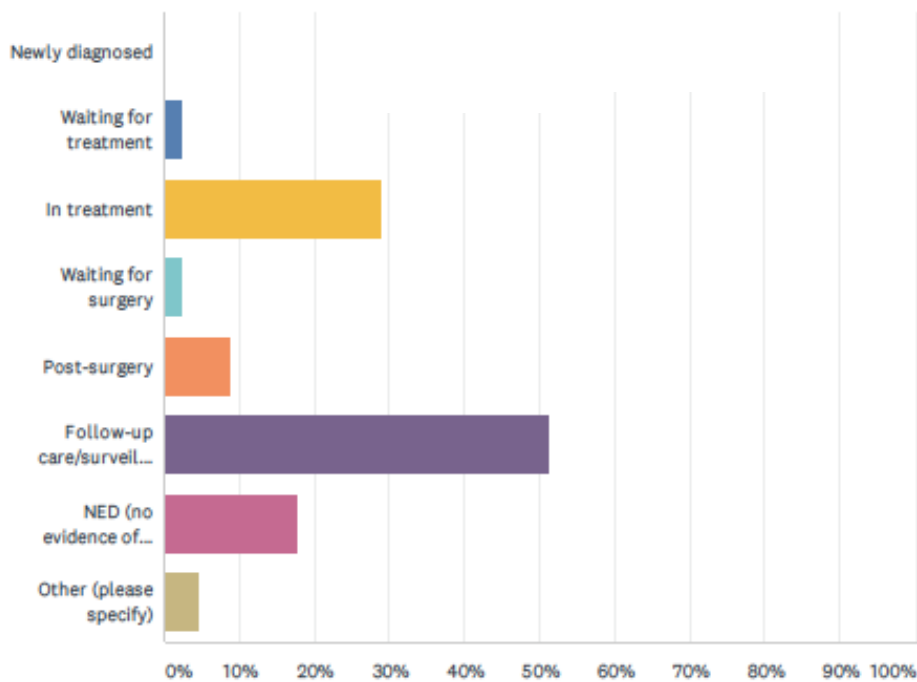


Fig. 2: “What best describes your stage of care? Check all that apply.”

QUESTION 5: “HAVE YOU HAD ANY DISRUPTIONS, CANCELLATIONS OR POSTPONEMENTS FOR THE FOLLOWING SITUATIONS? CHECK ALL THAT APPLY”

This question asked survey participants what issues they have encountered in receiving their regular care due to the COVID-19 pandemic. The options presented were “medical follow-ups,” “treatments,” “bloodwork,” “medical imaging,” “diagnostic testing,” “appointments for diagnosis and development of care plan,” “surgery, and clinical studies or research protocols. 38.2% of participants stated that they are having difficulty accessing medical “follow-ups with [their] doctors.” 26.47% of participants claimed that they are having difficulty receiving their treatments; 17.65%, difficulty getting bloodwork done; 11.76%, accessing medical imaging procedures; 8.82% mentioned diagnostic testing and diagnosis/care plan appointments individually; and 5.88% of participants have not received surgeries (as of the time of the survey) due to the pandemic. 32.35% of responses listed the difficulties they were having accessing care in the ‘other’ category. 2 of these were related to post-surgery care, and 1 response was from a healthcare professional who stated that their patients had been impacted by every option. 4 of these ‘other’ responses stated that they have had no issues being seen by healthcare professionals.

QUESTION 6: “TO WHAT DEGREE HAS COVID-19 CREATED DIFFICULTIES CONNECTING TO ANY TYPE OF HEALTHCARE PROVIDERS (GENERAL PHYSICIAN, CLINICIAN, NURSE, PHARMACIST, OR OTHER?)”

This question asked whether survey participants were having a difficult time getting in contact with healthcare professionals. 33.33% of respondents stated that they had not yet experienced any issues; 31.11%, have experienced some issues; 17.78%, have experienced several issues; and 11.11%, are anticipating that there will be disruptions in their contact with their healthcare team during COVID. 3 survey participants suggested that the question was not applicable to them, which is consistent with the number of responders that are either healthcare workers or are no longer receiving treatments.

This question also gave survey participants the option to write in responses, in case they wanted to elaborate or did not feel that the options given represented their experience. There were 10 responses to this section, 8 of which noted that they were having either phone or video consultations. 1 response stated that all of their appointments had been cancelled, 1 expressed anxiety that they will not be able to get appointments that they might need, and 2 said that the level of care they are currently receiving does not seem adequate.

QUESTION 7: “TO WHAT DEGREE HAS THE CONTINUITY OF YOUR ONCOLOGY CARE BEEN AFFECTED (OR WILL IT BE) BY THE COVID-19 PANDEMIC?”

Question 7 clarified to what extent the participants oncology-specific care has, or might be, affected by the pandemic. 34.09% of responses stated that they have had no issues thus far; 20.45%, are anticipating that there will be disruptions in their care; 18.18% said that they have experienced some disruption in their care; and 11.36% stated that they have experienced “a lot” of disruptions. 13.64%, of participants felt that the question was not applicable to them.

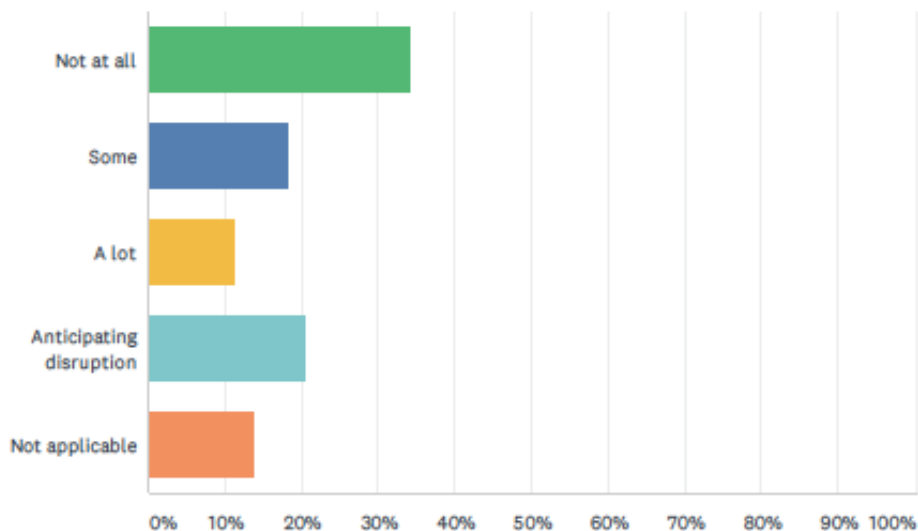


Fig. 3: “To what degree has the continuity of your oncology care been affected (or will it be) by the COVID-19 pandemic?”

QUESTION 8: “HAVE YOU RECEIVED, OR BEEN OFFERED, CONSULTATIONS WITH HEALTH PROFESSIONALS BY TELEPHONE OR VIDEOCONFERENCE SINCE FEBRUARY?”

This question asks whether survey participants have utilized, or been offered, telephone or videoconference medical appointments since the beginning of the shelter-in-place mandates in February. 66.67% of participants claimed that they have had, or been offered, telephone or videoconference appointments; 17.78% have not; and 15.56% said the question was not applicable to them.

Question 8 allowed participants to include additional details if they so desire. 7 participants added more information here, 6 of which specified what kind of appointments they have had via telephone or videoconference. 1 response, from a healthcare professional, stated that nearly all of their patients have had virtual care since February in order to minimize patient risk of contracting COVID-19.

QUESTION 9: “IF YOU ANSWERED ‘YES’ TO THE ABOVE QUESTION, HAVE YOU FOUND A TELEPHONE OR VIDEOCONFERENCE TO BE AN APPROPRIATE SUBSTITUTION FOR AN IN-PERSON APPOINTMENT?”

Question 9 asks participants who have had, or have been offered, telephone or videoconference appointments whether they have found these appointments a satisfactory replacement for an in-person appointment. The majority of responses, 52.38% stated that they found their distance appointments to be a suitable substitution for their regular appointments. 16.67% felt these distance options were not an appropriate substitution, and 30.95% said that the question was not applicable to them; some of these participants have likely not needed to have virtual or telephone appointments, and therefore also found question 8 to not be applicable.

This question also allowed participants to include more details, and 8 decided to add more information. Overall, these responses reflect a preference for in-person appointments, but understanding that distance appointments are necessary in this time.

QUESTION 10: “TO WHAT DEGREE HAS COVID-19 CREATED DIFFICULTIES IN RECEIVING DRUG THERAPY OR TREATMENT PRESCRIBED BY YOUR ONCOLOGIST, EITHER FOR YOUR CANCER OR FOR SIDE EFFECT MANAGEMENT?”

Question 10 asked whether survey participants were having difficulty receiving their scheduled care due to the COVID-19 outbreak. 35.56% of participants said that they have had no issues receiving care; 20.00% have had some issues; and 4.44% have had “a lot” of issues. 40% of participants stated that the question was not applicable to them.

This question also included the option for participants to write in more details, and 7 participants opted to do so. Of the 7 participants, 1 said that they are unable to access trial drugs, and 3 mentioned having to postpone appointments. The remaining written responses gave more details as to why they did not feel the question was applicable to them.

QUESTION 11: “IF YOU ANSWERED ‘SOME’ OR ‘A LOT’ TO THE PREVIOUS QUESTION, WHICH DRUG(S) OR TREATMENT(S) ARE YOU HAVING TROUBLE OBTAINING?”

Question 11, which asked participants to write in their responses, ascertained which drug(s) or treatment(s) the participants were having difficulty accessing due to the pandemic. About 1/3 of these responses stated that they were not having difficulty accessing treatment(s) or drug(s), or were not in the position to need them. The remaining responses ranged from routine appointments, prescription drugs, drug trial, and scheduled treatments or procedures.

QUESTION 12: “WHAT TYPE OF ONCOLOGY DRUGS DO YOU TAKE FOR YOUR TREATMENTS? CHECK ALL THAT APPLY.”

This question asked what category of oncology drugs the survey participants are taking for their treatments. The options available for participants to choose were “targeted therapy (oral),” “immunotherapy (intravenous),” “chemotherapy (intravenous),” “sub-cutaneous injection,” “not applicable,” and “other (please specify),” wherein participants had the option to write in treatments that were not listed. 25.58% of participants stated that they are taking immunotherapy (intravenous); 4.65% are taking targeted therapy (oral); 2.33% are taking chemotherapy (intravenous); and none of the participants selected sub-cutaneous injection. 4.65% selected other, and items listed here included liquid nitrogen and radiation therapy. 62.79% of participants stated that the question was not applicable to them, which suggests that they are either medical professionals, taking the survey on behalf of a family member, or no longer receiving treatments.

QUESTION 13: “TO WHAT DEGREE DO YOU HAVE CONFIDENCE IN THE ABILITY OF YOUR ONCOLOGY HEALTHCARE TEAM TO PROVIDE APPROPRIATE CARE AND TREATMENT TO YOU AT THIS TIME?”

Question 13 asks participants whether they feel their healthcare team can continue to provide them with the care they need during the COVID-19 pandemic. 37.78% of participants selected “a lot,” 33.33% have “some” confidence in their healthcare team, and 4.44% expressed having no trust in their healthcare team during this time. 22.22% of participants felt that the question was not applicable to them.

This question also gave participants the option to write in more details. One of these responses noted that a critical service to them has been cancelled, and another mentioned that they now have to drive a long distance to their appointments, despite their illness.

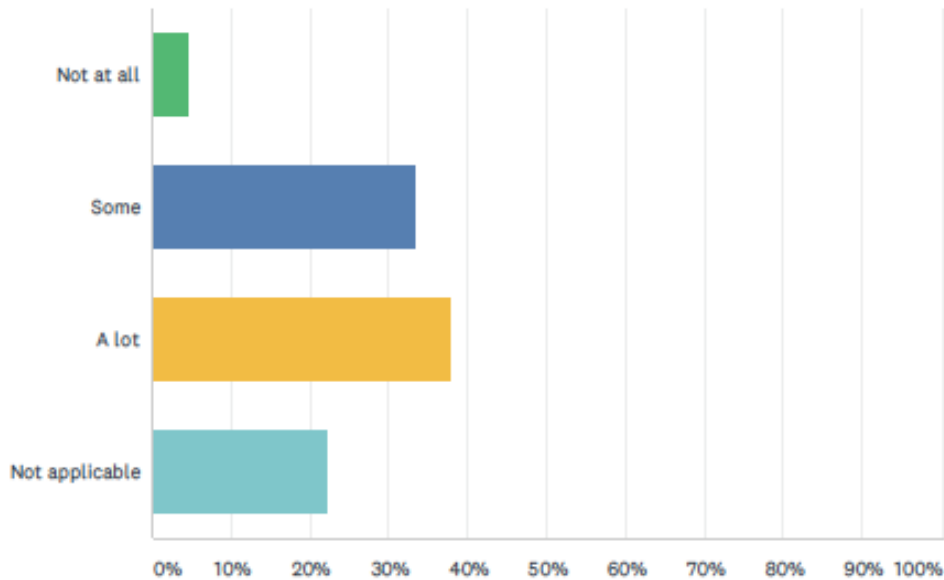


Fig. 4: “To what degree do you have confidence in the ability of your oncology healthcare team to provide appropriate care and treatment to you at this time?”

QUESTION 14: “IS THIS PANDEMIC CAUSING YOU MORE ANXIETY THAN USUAL, OR AGGRAVATING YOUR EXISTING MENTAL HEALTH ISSUES?”

This question asked participants whether the pandemic has caused an increase in their anxiety levels. The majority, 53.33%, stated that their anxiety has increased somewhat; 33.33% that it has increased their anxiety a lot; and 11.11% said not at all. 2.22% said that the question was not applicable to them. Clearly, the results of this question suggest that the COVID-19 pandemic, and the resulting changes in healthcare for cancer patients, are a cause of anxiety for survey participants.

More details about this anxiety can be found in the responses patients wrote in to this question. Half of these written responses cite being immunocompromised due to cancer as their primary concern, while the other half mentioned mental health difficulties surrounding isolation.

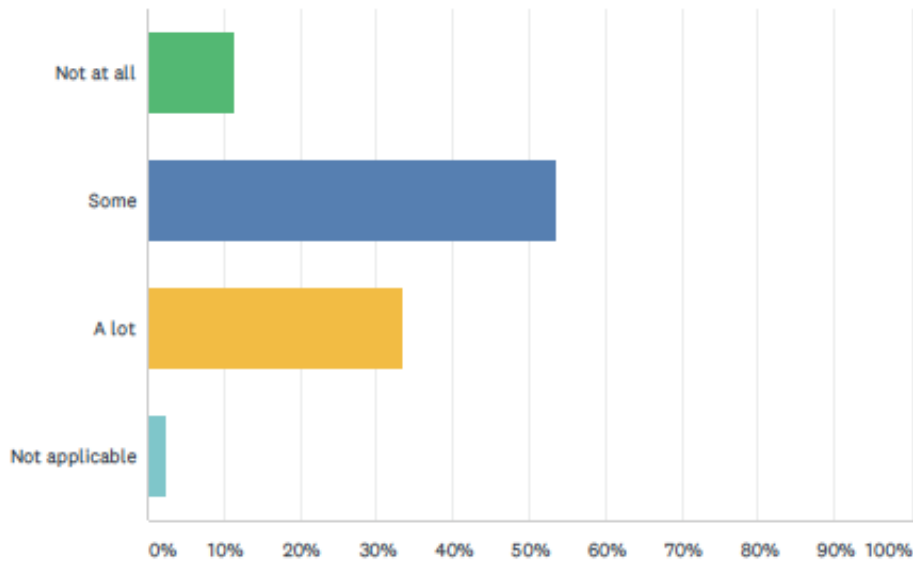


Fig. 5: “Is this pandemic causing you more anxiety than usual, or aggravating your existing mental health issues?”

QUESTION 15: “TO WHAT DEGREE HAS COVID-19 AFFECTED YOUR EMOTIONAL WELLBEING? CHECK ALL THAT APPLY.”

Question 15 elaborated on the previous question by asking what specific aspects of the COVID-19 outbreak are causing the survey participants to experience heightened anxiety. The choices available were “experiencing anxiety, fear, stress, or overwhelm for yourself or others,” “experiencing loneliness or isolation,” “[feeling] emotionally withdrawn,” “experiencing fear that you or others are more at risk for COVID-19 complications,” and “experiencing frustration or anger.” Participants were also invited to select “other” and fill in alternative answers. 55.56% of participants expressed fear that they are more at risk for COVID-19 due to being immunocompromised; 48.89% are having anxiety and stress for themselves or others; 31.11% are experiencing loneliness or isolation; 28.89% are experiencing frustration or anger; and 17.78% are [feeling] emotionally withdrawn. 22.22% of participants filled in ‘other’ responses. Comments in this section included job loss, boredom, and not getting enough time outdoors.

QUESTION 16: “TO WHAT DEGREE HAS COVID-19 AFFECTED YOUR QUALITY OF LIFE? CHECK ALL THAT APPLY.”

This question asked about the medical and social affects of COVID on the survey participants. 45.24% selected “experiencing difficulty accessing information related to COVID-19,” 42.86% “experiencing difficulty attending appointments or seeking necessary healthcare because of fear of exposure to COVID-19,” and 7.14% “experiencing difficulty accessing information needed related to COVID-19.” 30.95% of participants selected “other,” and filled in responses. Several responses here included social isolation, and others mentioned missing daily routines, and feeling overwhelmed.

QUESTION 17: “TO WHAT DEGREE HAVE YOU EXPERIENCED DIFFICULTIES ACCESSING FOOD AND/OR FOOD DELIVERIES?”

Question 17 assessed the food security of the survey participants. 48.89% stated that they are having no difficulties, 46.67% are having some level of difficulty, and 2.22% mentioned having “a lot” of trouble. 2.22% thought that the question was not applicable to them. Some participants chose to provide additional responses to this question, which included the difficulties of navigating grocery stores at this time, and ingredient shortages.

QUESTION 18: “TO WHAT DEGREE HAVE YOU EXPERIENCED DIFFICULTIES ACCESSING TRANSPORTATION?”

This question ascertained the extent to which survey participants are having trouble accessing transportation. The vast majority of survey participants, 75.56%, are not having any difficulties accessing transportation; 15.56% are having some difficulties; and 4.44% are having a lot of difficulty. 4.44% felt that the question was not applicable to them.

QUESTION 19: “TO WHAT DEGREE HAVE YOU EXPERIENCED DIFFICULTIES STAYING CONNECTED WITH FRIENDS AND FAMILY?”

Question 19 gauged whether survey participants are having difficulty keeping in touch with their friends and family. The majority of participants, 64.44%, said that they are having some difficulty keeping in touch with their community; 17.78% are having no difficulty; 15.56% are having “a lot” of difficulty; and 2.22% said that the question was not applicable to them. Nearly all of the additional responses mentioned video conferencing and phone calls as methods to keep in touch, while some of the comments mentioned the difficulties of having slower internet.

QUESTION 20: “HAVE YOU EXPERIENCED OTHER PROBLEMS THAT HAVE NOT BEEN IDENTIFIED IN RELATION TO THE COVID-19 PANDEMIC THAT YOU WISH TO COMMUNICATE TO US?”

This question asked survey participants whether COVID-19 is causing any issues for them that have not been mentioned thus far in the survey. Responses to this question included several mentions of being immunocompromised, and therefore at higher risk; worry about their friends and family; being unsure how to talk to the people around them about cancer, as everyone is more stressed; and mental health difficulties, such as depression and loneliness.

QUESTION 21: “WHAT IS YOUR GREATEST CONCERN AND/OR NEED IN THE CURRENT SITUATION?”

The final question in this survey asked participants to write in any other concerns or needs that they have in the context of the COVID-19 pandemic that have not been mentioned thus far in the survey. Several of these comments reiterated concerns about not being able to access medical appointments, and anxieties about contracting COVID. Other concerns included the national economy, their own financial stability, missing their friends and family, and being restless.

FRENCH SURVEY RESULTS

From April 15th, 2020— April 27th, 2020, Save Your Skin Foundation ran a concurrent patient survey titled “Impact de la pandémie de COVID-19 sur les patients Canadiens atteints de mélanome, de mélanome oculaire et de cancer de la peau non mélanome,” which was directed toward French Canadian melanoma, ocular melanoma, and non-melanoma skin cancer patients. The French survey consisted of the same 21 question as the English survey outlined above. The majority of participants (83.33%) are currently living with melanoma, ocular melanoma, or non-melanoma skin cancer, while 16.67% categorized themselves as neither a patient or caregiver. None of the survey participants identified as a formal or informal caregiver (Question 1). The majority of French

survey participants are melanoma patients (66.67%), with the other 33.33% divided evenly between Basal Cell Carcinoma and Squamous Cell Carcinoma (question 3). 66.67% of these patients are in follow-up care/surveillance, with the remainder split between newly diagnosed patients and those currently in treatment (question 4). 100% of the French survey participants are from Québec (question 2).

In terms of medical disruptions related to COVID-19, the results were relatively consistent across the surveys. Notable exceptions include the larger quantities of postponed surgeries reported by patients in the French survey relative to the English survey (question 5). Patients taking the French survey also are not reporting current difficulties with reaching their healthcare professionals, however, the French survey participants professed an extremely high feeling that there will be future disruptions in their care (question 6). It was more difficult to ascertain which treatments the participants of the French survey are having difficulty accessing, as the majority of the French survey participants are no longer in treatment (question 12). Overall, however, the issues of medical and financial security, and mental health, are being felt consistently across the English and French surveys.

CONCLUSION

The results of these surveys suggest that cancer patients across Canada are experiencing the same COVID-related social and financial anxiety as others. However, they also have the added stress of navigating an already complex medical system in this time, having treatments rescheduled and appointments online, and being higher risk. At this time, it is imperative that we keep in mind segments of the population who are having particular difficulty at this time, and support them however we can.