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Survey: The Patient Experience

Systemic Treatment of Adult Cutaneous Melanoma

Save Your Skin Foundation
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Table of Contents and Figures

INTRODUCTION	3
REPORT ON SURVEY DATA	4
QUESTIONS 1-5: SURVEY DEMOGRAPHICS	4
<i>Fig. 1: Question 1: What is your gender?</i>	4
<i>Fig. 2: Question 2: What is your age?</i>	4
<i>Fig. 3: Question 3: Which of the following best describes your employment status?</i>	5
<i>Fig. 4: Question 4: If you live in Canada, in what province/territory do you reside?</i>	5
QUESTIONS 6-9: EXPERIENCES WITH CANCER DIAGNOSIS AND SIDE EFFECTS	6
<i>Fig. 5: Question 6: What stage of melanoma have you been diagnosed with? Select all that apply.</i>	6
QUESTIONS 10-12: TREATMENT EXPERIENCES	7
<i>Tab. 1: Question 10: What melanoma treatment(s) have you received and at what stage(s)?</i>	7
<i>Fig. 6: Question 11: What was your experience with those treatments?</i>	8
<i>Fig. 7: Question 12: If you received or are about to receive a treatment in stage 2 or 3 and your disease was to reoccur at a later stage, what do you feel would be reasonable next steps or options to ask your medical team about? For instance, would you think it reasonable to receive additional.....</i>	9
<i>treatment(s)? Please explain.</i>	9
QUESTIONS 13-14: PATIENT FEEDBACK ON CARE OPTIONS	9
QUESTIONS 15-19: PATIENT EXPERIENCES ON KEYTRUDA™	10
<i>Fig. 8: Question 15: If you received Pembrolizumab (Keytruda™) for stage II.....</i>	10
<i>melanoma, how did you obtain this treatment?</i>	10
<i>Fig. 9: Question 16: Did you complete the full course of treatment? If not, please explain why.</i>	11
<i>Fig. 10: Question 18: Were the side effects manageable?</i>	11
<i>Fig. 11: Question 19: If you experienced side effects from this drug therapy, did the benefits of the treatment outweigh the experience of the side effects?</i>	12
QUESTIONS 20-22: ACCESS, FUNDING, AND TREATMENT HARDSHIPS.....	12
<i>Fig. 12: Question 20: Did you experience any hardships that barred you from accessing this drug therapy? Was the treatment readily available to you? Hardships could mean having to travel long distances; not having quick access to treatment or having to personally pay the cost of therapy, for example. Please explain.</i>	13
.....	13
<i>Fig. 13: Question 22: If you were to be offered a drug therapy on a.....</i>	13
<i>clinical trial, would you consider taking it?</i>	13
CONCLUSION	14

Introduction

From April 11-April 26, 2022 the Save Your Skin Foundation (SYSF) disseminated the survey “The Patient Experience: Systemic Treatment of Adult Cutaneous Melanoma” in both English and French language versions. The purpose of the survey was to gather patient-reported experience measures (PREMs) related to the experiences of adults with cutaneous melanoma in terms of side effects, holistic experiences (mental wellness, financial considerations, quality of life), and their feelings about the care options currently on the market. One segment of the survey particularly solicited information from participants who received Pembrolizumab (Keytruda™) for stage II melanoma. The following report contains the combined results of both the English and French surveys into one data set.

Quotation marks surrounding patient responses indicate that this option was one that survey participants were given as an option in the survey, such as in a multiple choice or sliding scale question; these indicate that the response was filled from the survey body. Responses without quotation marks indicate that we are summarising either individual or collective responses from questions where patients were asked to write in their thoughts. As many of the questions asked participants to write in responses, please be aware that these idiosyncratic responses mean we have, in some cases, grouped similar responses together to form data sets and eliminated responses that are not relevant to the question at hand, unless they are especially illuminating. In cases where written responses include multiple ideas, we incorporate all of these individually into our data. Thank you for taking the time to read this report; if you require any more information, please email info@saveyourskin.ca.

Report on Survey Data

Questions 1-5: Survey Demographics

The first five questions in the survey ascertained the overlapping demographics of participants. The responses demonstrated that participants were 68% “female” and 32% “male” (Q1, fig. 1) and were mostly evenly distributed across 30-79 years of age (Q2). In terms of employment status, the largest group of participants were “retired” (44%), followed by those who identified as “employed, working full-time” (28%) (Q3). Participants were entirely from the Western provinces (up to and including Ontario), with the largest number being the 36% from “British Columbia” (Q4). Question 5 asked participants who did not live in Canada where they reside, and the only non-Canadian participant noted that they are from Henderson, Nevada, USA.

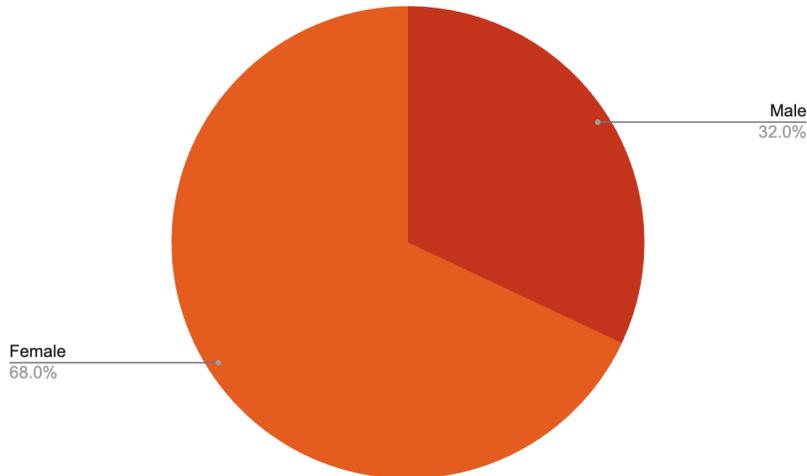


Fig. 1: Question 1: What is your gender?

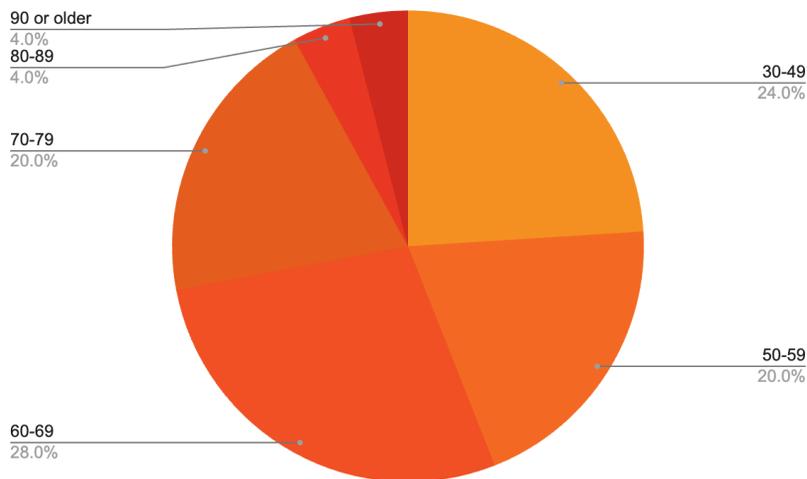


Fig. 2: Question 2: What is your age?

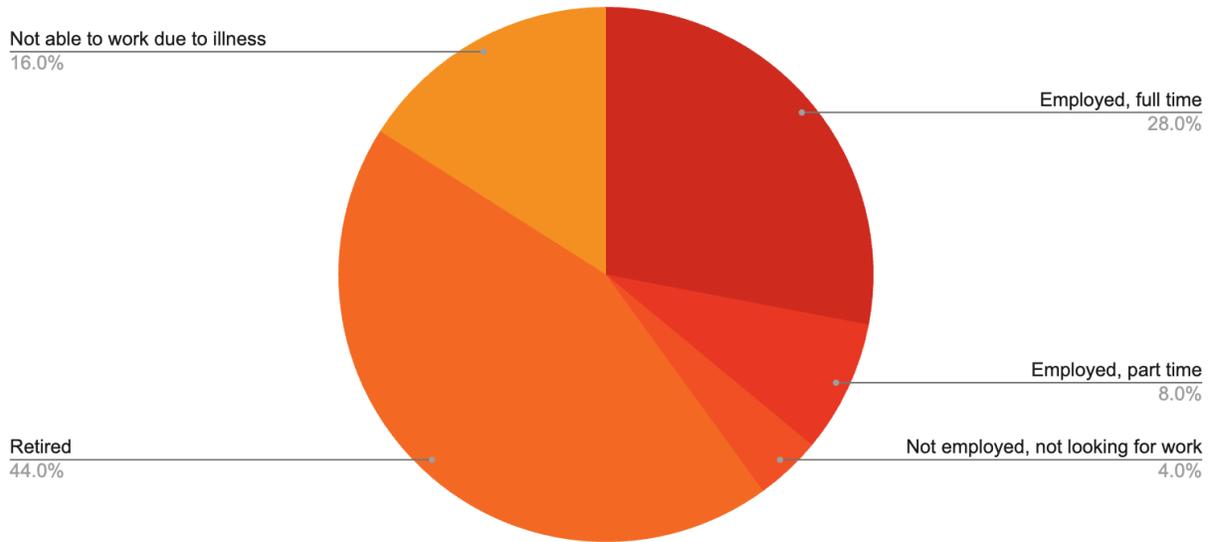


Fig. 3: Question 3: Which of the following best describes your employment status?

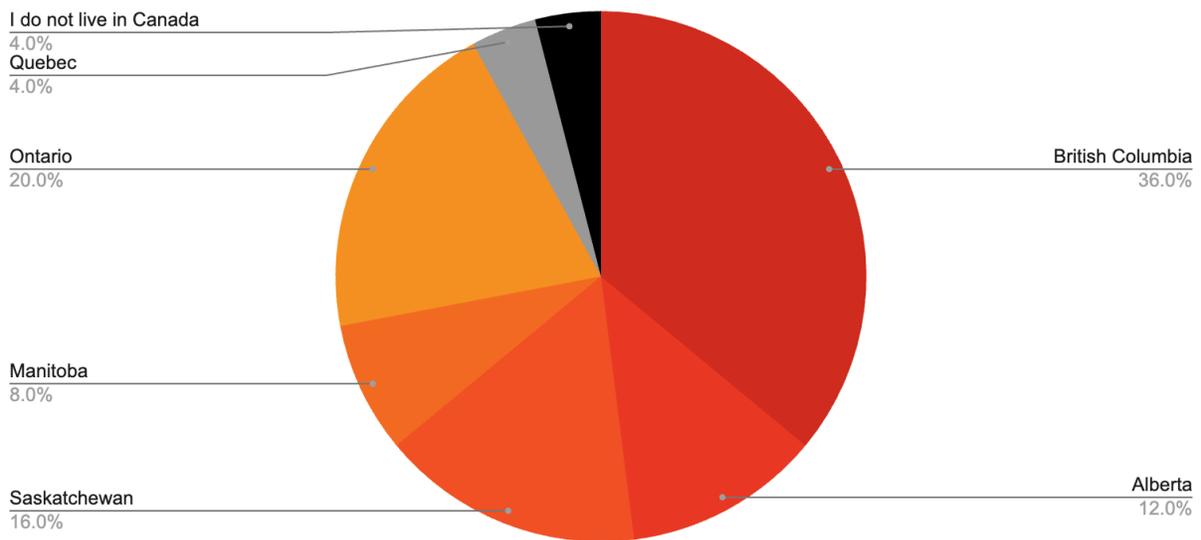


Fig. 4: Question 4: If you live in Canada, in what province/territory do you reside?

Questions 6-9: Experiences with Cancer Diagnosis and Side Effects

The survey then shifted to discuss participants experiences with melanoma. Question 6 established that most survey participants had been diagnosed with late-stage melanoma, with 52% diagnosed with “stage IV” and 48% with “stage III” (Q6). Question 7, which asked participants their diagnosis year, established that 16% were diagnosed in “2020” and “2019” individually, 12% in “2018,” “2017,” “2016,” and “2013” individually, 8% in “2012”, and 4% in “2015,” “2014,” and “2005” individually (Q7).

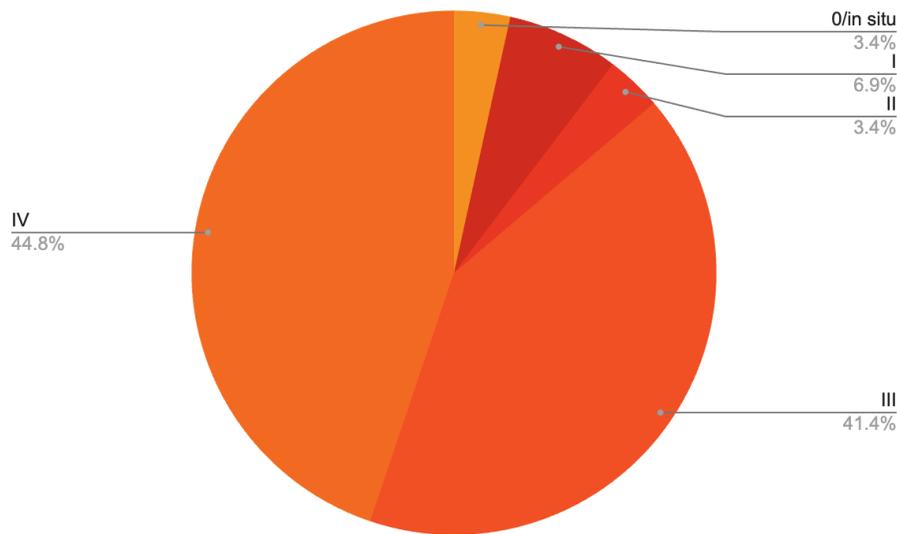


Fig. 5: Question 6: What stage of melanoma have you been diagnosed with? Select all that apply.

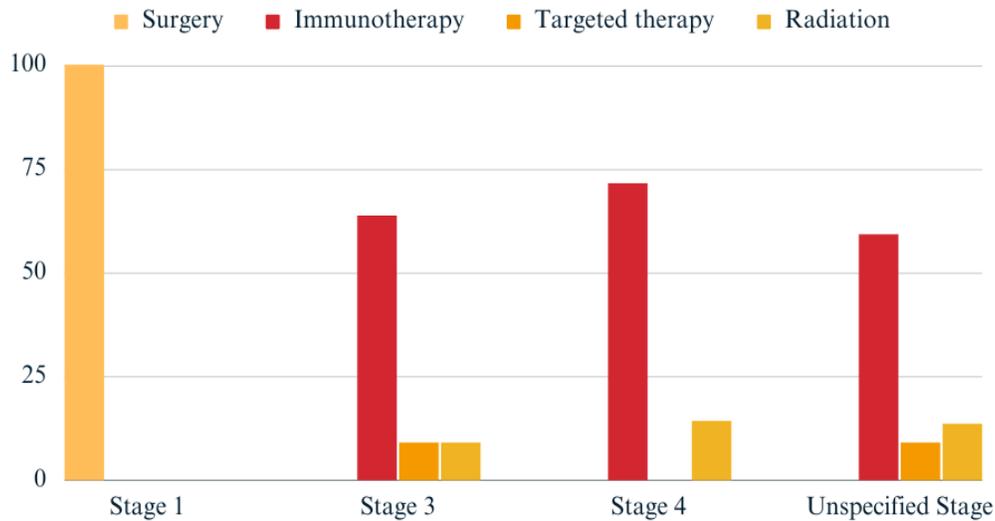
Question 8, “what has been your experience with this type of cancer? For example, physical, mental, financial, emotional toll etc.,” asked participants to write in descriptions of their experiences with melanoma. The most frequent descriptors listed by participants were mental stress and exhaustion (24%) and fatigue (24%), followed in frequency by anxiety (20%), physical side effects (16%), and financial difficulties (16%) (Q8). Ordered by in decreasing frequency, other responses included the phrases “scary” (12%) and “challenging” (8%), followed by mentions of depression (8%), insomnia (4%), COVID-related difficulties (4%), having to travel for care (4%), a lack of confidence in the medical system (4%), fear of death (4%), skin rashes (4%), arthritic pain (4%), difficulty swallowing (4%), and the phrases “devastating” and “difficult on all fronts” (4%) (Q8). More positive experiences patients reported include that they are feeling surprisingly good (8%), that they are experiencing minimal side effects (4%), and that they are feeling lucky due to being diagnosed early (4%) and receiving treatment (4%) (Q8).

When asked to list their ongoing physical symptoms in question 9, “do you have any ongoing symptoms with this type of cancer? If yes, please list them,” participants most frequently noted that they were experiencing no continuing physical symptoms (36%) (Q9). Long-term physical symptoms that were mentioned include “metastasis or recurrence” (16%), fatigue (12%), lymphedema (8%), and edema (8%) (Q9). Symptoms that were each mentioned

by 4% of participants include “joint pain,” “thyroid dysfunction,” “confusion,” “memory loss,” “vitiligo,” “skin itching,” “retinopathy,” “swelling,” “reduction of vision,” “tinnitus,” “hypothyroidism,” “avascular necrosis,” “colitis,” “mobility issues,” “brain fog,” and “ganglion pain” (Q9).

Questions 10-12: Treatment Experiences

Question 10 asked survey participants which treatments they received at which disease stage. Please see table 1 for a visualisation of how care types were distributed across disease stages in this population (Q10). The most popular treatments among participants who specified that they received treatment in stages 3 and 4, the most cited stages, were immunotherapy in both groups (63.63% in stage 3, 71.42% in stage 4) (Q10). Immunotherapy was also the most cited treatment among participants who did not specify at which stage they received treatment, with 59.09% (Q10).



The numerical values in the y-axis of this graph are percentages.

Tab. 1: Question 10: What melanoma treatment(s) have you received and at what stage(s)?

Following in question 11, survey participants were asked about their experience receiving the care they listed in the previous question (Q11). The most frequent response was that the patient has experienced ongoing side effects from treatments (25%) (Q11). This was followed by 24% of participants noting that the treatment process has overall been better than expected, and 20% claiming that they had side effects earlier in their treatment, but these have subsided, and 12% that they are switching treatments due to side effects (Q11). Further, 8% mentioned having no significant side effects, and 4% each learned a lot about the Canadian medical system, are experiencing side effects but can continue work at their jobs, felt that treatment went as expected, and found treatment emotionally draining (Q11).

Question 12 asked participants what they feel a reasonable next step would be for them if they should experience a recurrence (Q12). 41.66% of responses said they would consider additional treatments (Q12). Other responses qualified under which circumstances they would consider additional treatment, with 29.16% saying they would need to investigate all of the options before making this decision, 8.33% each writing that they would want to see if there are treatments that might be more effective for them than those previously tried and that it would depend on the side effect profiles of their other treatment options, and 4.16% responded that they were ultimately unsure (Q12). 12.50% of participants either indicated that the question was not applicable to them or did not respond (Q12). The figure depicting data for this question is on the next page (fig. 7, pg. 8).

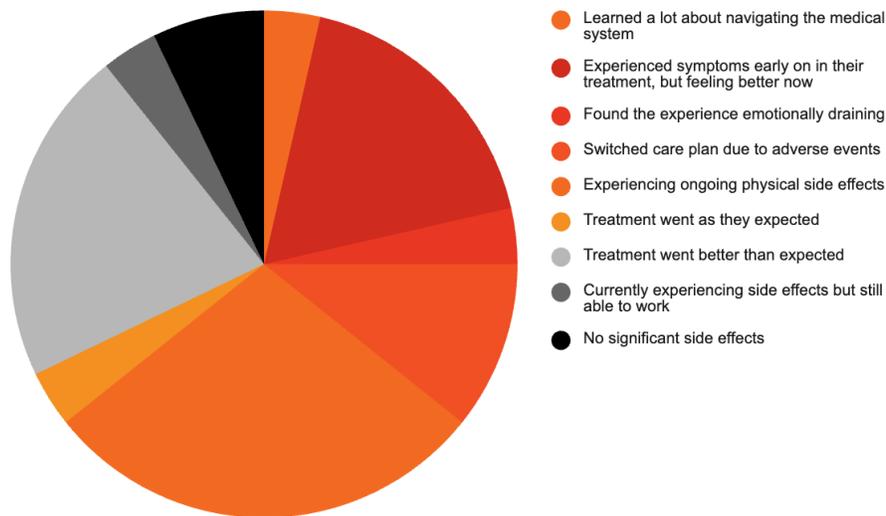


Fig. 6: Question 11: What was your experience with those treatments?

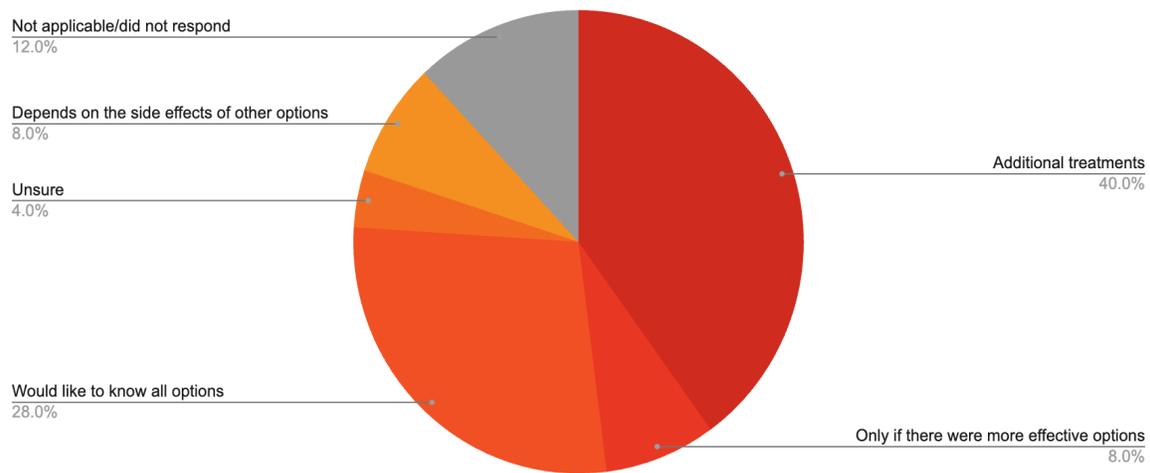


Fig. 7: Question 12: If you received or are about to receive a treatment in stage 2 or 3 and your disease was to reoccur at a later stage, what do you feel would be reasonable next steps or options to ask your medical team about? For instance, would you think it reasonable to receive additional treatment(s)? Please explain.

Questions 13-14: Patient Feedback on Care Options

In question 13, patients were asked what kind of improvements they would like to see in new treatments coming to market. The most frequent suggestion (12%) was a better side effect profile (Q13). This was followed by 8% each mentioning a desire for more immunotherapy options, greater awareness surrounding treatments, and more DNA or mutation-customizable treatments, and 4% highlighted each of the following: the need for more treatments that are accessible in rural areas, fewer pills to be taken at home, more flexibility in stage-based drug eligibility, the more frequent use of immunotherapy as a first-line treatment, more options for ocular melanoma, immunotherapy treatments that are covered by insurance, the ability to combine treatments with steroid medications, faster drug approval, and more melanoma specialists in Canada (Q13). 24% of responses noted that they had no opinion regarding improvements for incoming treatments (Q13).

Question 14 asked participants how the quality of life for them and other patients would change if there were more treatments that had been improved in the ways suggested in question 13. 25% wrote that the sustained quality of life on immunotherapy means that there would be no trade-offs between quality of life and receiving life-saving treatment and a further 12.50% noted that there would be increased predictive testing for side effects (Q14). Each of the following were mentioned by 4.16% of participants: more people get to live with greater access to treatments, patients would have more support during the treatment process, there would be more treatment options for patients to choose from, patients could access a second line of treatment if the first is unsuccessful, and immunotherapy would be more widely available (Q14). 25% of participants opted not to answer the question, 8.33% said they were unsure, and there were

several either complete responses or aspects of responses which did not directly answer the question (Q14).

Questions 15-19: Patient Experiences on Keytruda™

Question 15 was directed at survey participants who have received Pembrolizumab (Keytruda™) for stage II melanoma (Q15). 17.65% of responses indicated that they received Keytruda™ through via “clinical trial” (Q15). Another 23.52% received this drug through a “private payer” and the same amount had “compassionate access” (Q15). Of the participants who selected “other,” most indicated that they have not received Keytruda™; two, however, specified that their treatment was paid for by private insurance; these responses have been added to the “private payer” percentage (Q15).

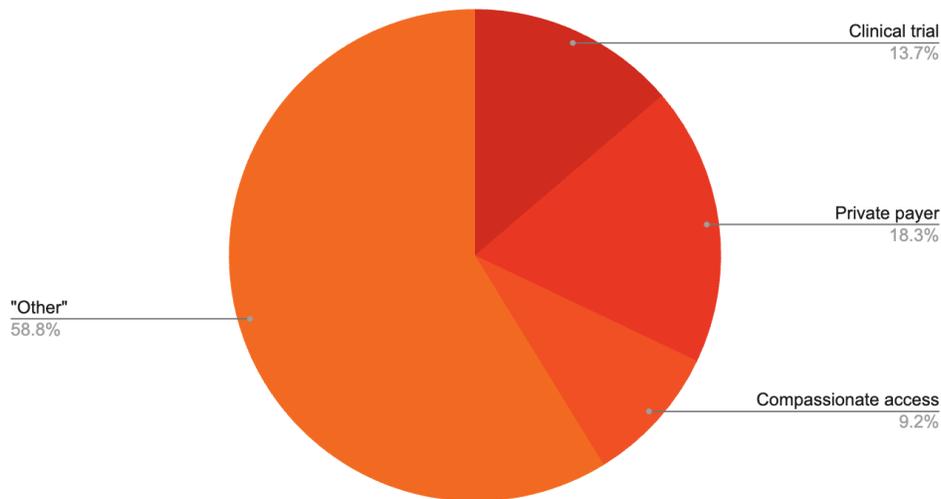


Fig. 8: Question 15: If you received Pembrolizumab (Keytruda™) for stage II melanoma, how did you obtain this treatment?

Question 16 asked participants if they had completed their full course of treatment. 78.94% indicated that “yes,” they have; 10.52% responded “no,” they did not; and 10.52%, at the time of the survey, were “still in treatment” (Q16). Those who selected “no” chose not to elaborate on their circumstances (Q16). The figure representing data from question 16 is on the following page (fig. 9, pg. 11).

Question 17 asked participants what side effects they experienced during their treatment. The most cited side effect was “fatigue” (70%), followed by “skin rash” (40%), “cognitive impairment” (25%), “organ damage” (20%), “gastrointestinal issues” (20%), “loss or gain of appetite” (15%), “weight loss or weight gain” (10%), “nausea or vomiting” (5%), and “headaches” (5%) (Q17). Other side effects noted by individuals in the comment section included muscle loss, hot flashes, joint pain, depression, anxiety, arthritis, and dysphagia (Q17).

Question 18 asked whether survey participants found the side effects mentioned in question 17 manageable. The majority (63.15%) cited their side effects as “manageable” (Q18). A further 5.26% each cited their side effects being “somewhat manageable” and “neutral” (Q18). On the less tolerable side, 10.52% found their side effects to be “somewhat manageable” and 5.26% “not manageable” (Q18). 10.52% of participants indicated that the question was “not applicable” to them (Q18). The figure representing data from question 18 is on the following page (fig. 10, pg. 11).

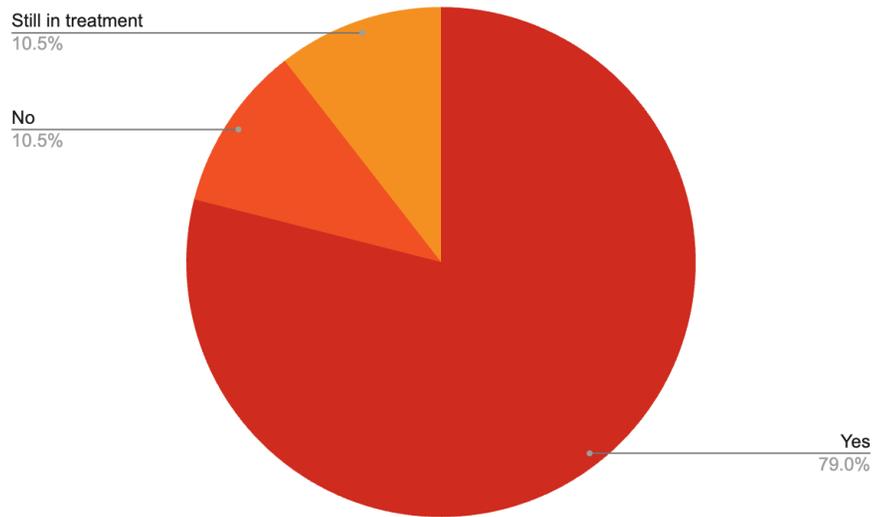


Fig. 9: Question 16: Did you complete the full course of treatment? If not, please explain why.

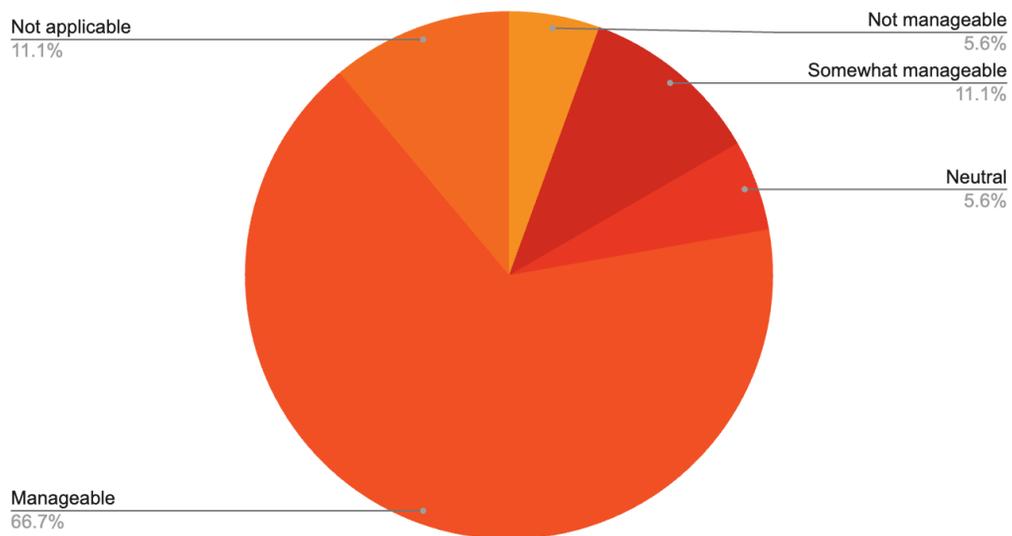


Fig. 10: Question 18: Were the side effects manageable?

Following up on question 18, question 19 asked participants whether they found that the benefits of their treatments outweighed the side effects. Most participants (85.71%) indicated that “yes,” the increased chances of survival offered by their treatment outweighed the side effects endured (Q19). Zero participants selected “no” and 4.76% were “not sure” (Q19). 9.52% stated that the question was “not applicable” to their situation (Q19).

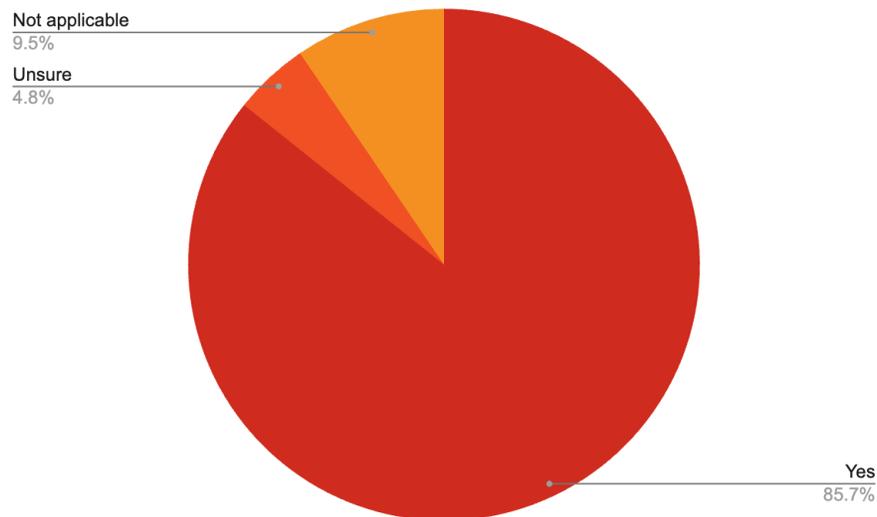


Fig. 11: Question 19: If you experienced side effects from this drug therapy, did the benefits of the treatment outweigh the experience of the side effects?

Questions 20-22: Access, Funding, and Treatment Hardships

Question 20 asked participants to indicate what hardships they experienced when accessing care. Fortunately, 40% of participants suggested that they did not experience any barriers to treatment access (Q20). Access issues that were listed included travelling long distances, which was selected by 15% of participants, being denied funding (10%), and eligibility-related access issues (10%) (Q20). More positive notes included 15% of patients mentioning that their treatment was covered by insurance and 5% having it covered by compassionate access; a further 5% wrote that they were pleased to be included in a trial (Q20).

In question 21, patients were asked to describe both the positive aspects of their treatment experience and to indicate what they, as a patient, look for in new treatments. Positive aspects participants listed included that innovative treatments are lifesaving (35%) and they are critically important to patients (35%); other participants felt lucky to receive treatment (10%) and 5% are excited about how quickly new treatments are being developed (5%) (Q21). In terms of further improvements to treatments on the market, patients noted that treatment access could be improved (10%), experimental treatments should be covered by insurance (10%), there should be more options for testing related to drug-matching (5%), more geographical options for receiving treatments (5%), and continuously improving regression-free survival (5%) (Q21).

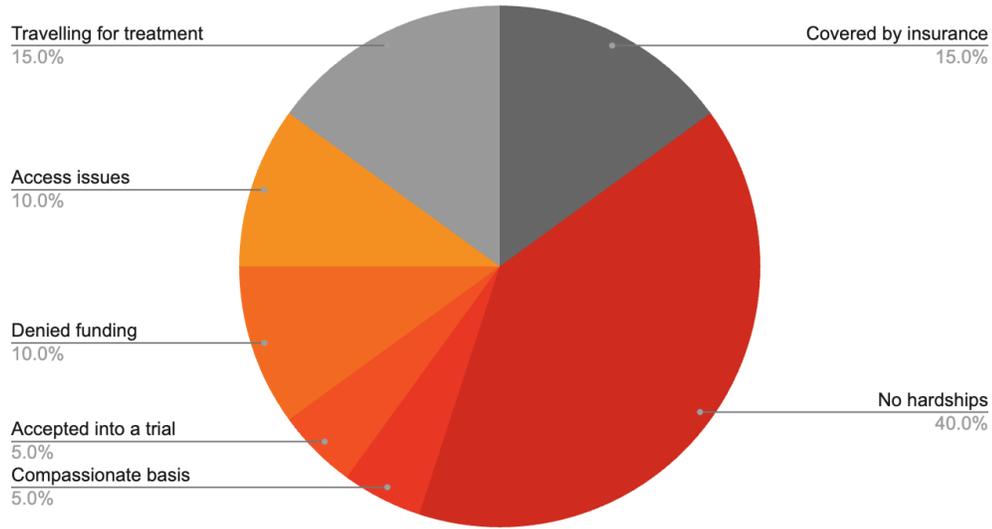


Fig. 12: Question 20: Did you experience any hardships that barred you from accessing this drug therapy? Was the treatment readily available to you? Hardships could mean having to travel long distances; not having quick access to treatment or having to personally pay the cost of therapy, for example. Please explain.

The final question in the survey, question 22, assessed participants’ general openness to a clinical trial, should they be hypothetically offered one. 78.26% said “yes,” they would receive a clinical trial; 21.73% responded that they were “not sure,” implying that this would depend on circumstance; and 0% would not consider a clinical trial (Q21).

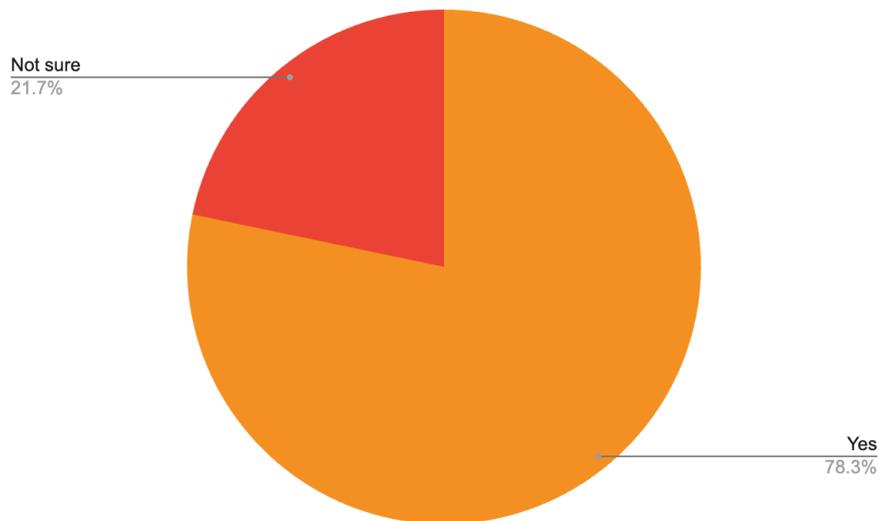


Fig. 13: Question 22: If you were to be offered a drug therapy on a clinical trial, would you consider taking it?

Conclusion

We learned several notable things in this survey. Patients continue to want access to innovative treatments and are interested in being offered trials (Q22). Patients, more than anything want to live; they view the life-saving benefits of treatment to be a worthwhile trade for the downsides (side effects, geographical and financial barriers) and would undergo additional treatments should they experience a recurrence (Q19, 12). More patients, too, are having better experiences on treatment; in question 11, when asked what their time on treatment has been like, 56% had positive things to say. 66.7% of patients who underwent Keytruda™ found any side effects they developed “manageable,” 79% finished their full course of Keytruda™, and 40% reported experiencing no hardships when accessing treatment (Q 18, 16, 20).

There is still work to do to improve. Despite all of the positive data listed above, the responses to question 8 demonstrate that cancer diagnosis and treatment is still a physically, mentally, and emotionally challenging experience. 25% of participants reported having encountered some type of hardship when accessing care, be it financial, eligibility criteria, or having to travel (Q20). Further, 86.2% of participants were diagnosed with either stage III or IV melanoma, suggesting that there are still efforts to be made in prevention and awareness measures to increase early diagnosis (Q6).

We also continue to see that patients are an excellent data set and patient-reported experience measures (PREMs) are an excellent tool for identifying patient needs, what aspects of the patient experience is improving, and what gaps still exist. We thank you for reading this report and, most importantly, we thank the patients who took the time and energy to offer their thoughtful responses.