



“Melanoma Treatment in the Adjuvant Setting”

A 2018 Patient Survey by Save Your Skin Foundation

Save Your Skin Foundation, September 2018

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From September 3rd, 2018— September 9th, 2018, Save Your Skin Foundation ran a patient survey titled “Melanoma Treatment in the Adjuvant Setting.” The survey consisted of 28 questions, which ranged between multiple choice, multi-selection, and write-in, and participants had the option to skip any question. While Save Your Skin is a Canadian patient group, the survey was open to international participation. The goal of the survey was to assess the impact melanoma has on patients and their families and caregivers, and get a picture of the treatment plan of the average melanoma patient, what treatment access limitations they have encountered, and what they look for in potential treatment options. For the sake of brevity, written answers are not included, and are grouped by topic. For access to the full survey results, contact the Save Your Skin Foundation at info@saveyourskin.ca.

QUESTION 1: “ARE YOU MALE OR FEMALE?”

The first question of the survey assesses the gender identification breakdown of the survey participants. The available options were “male” or “female.” 81.25% of participants identified as female, while 18.75% identified as male.

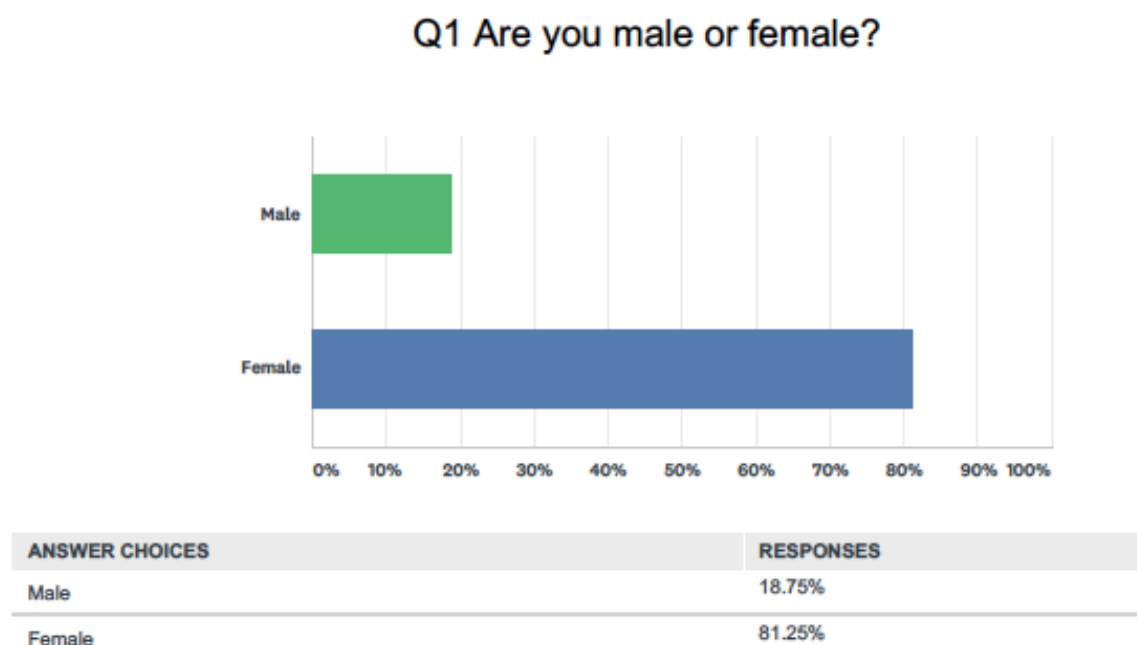


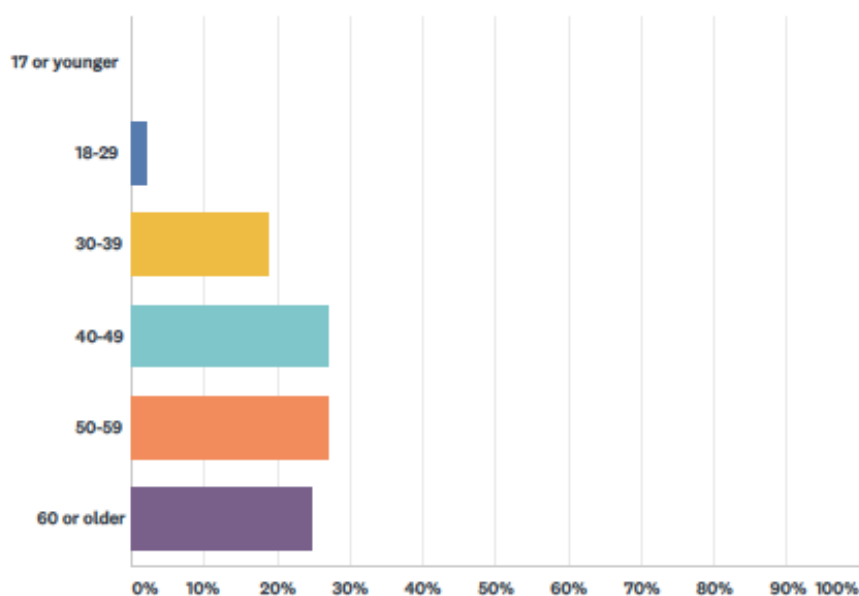
Figure 1: “Question 1: Are you male or female?”

QUESTION 2: “WHAT IS YOUR AGE?”

The second question determines the age bracket(s) of the survey participants. The possible answers were “17 or younger,” “18-29,” “30-39,” “40-49,” “50-59,” or “60 or older.”

2.08% of participants identified as being in the 18-19 bracket, 18.75% as being in the 30-39 bracket, 27.08% as being in the 40-49 bracket, 27.08% as being in the 50-59 bracket, and 25.00% as being in the 60 or older bracket.

Q2 What is your age?



ANSWER CHOICES	RESPONSES
17 or younger	0.00%
18-29	2.08%
30-39	18.75%
40-49	27.08%
50-59	27.08%
60 or older	25.00%

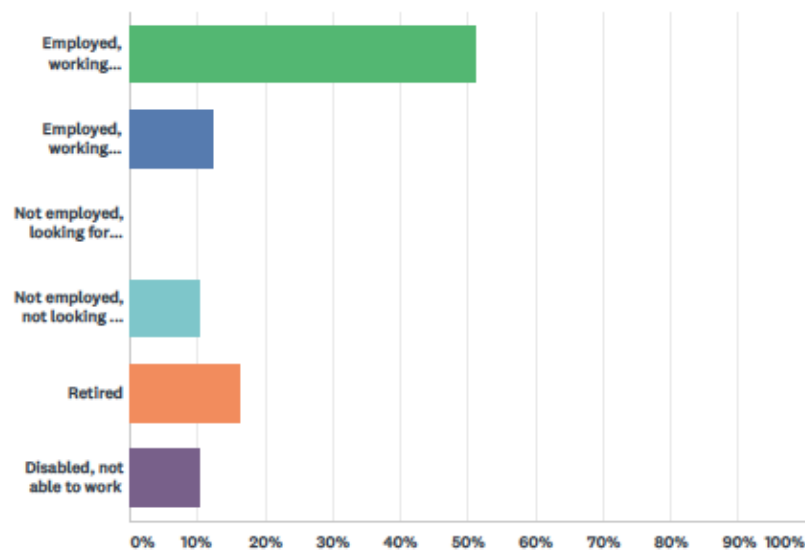
Figure 2: “Question 2: What is your Age?”

QUESTION 3: “WHICH OF THE FOLLOWING BEST DESCRIBES YOUR EMPLOYMENT STATUS?”

Question 3 ascertains the employment status of the survey participants. The available answer choices were “employed, working full-time;” “employed, working part-time;” “not employed, looking for work;” “not employed, not looking for work;” “retired;” and “disabled, not able to work.”

51.02% of participants identified as employed and working full time, 12.24% as employed, working part time, 10.20% as not employed, not looking for work, 16.33% as retired, and 10.20% as disabled and not able to work.

Q3 Which of the following best describes your employment status?



ANSWER CHOICES	RESPONSES
Employed, working full-time	51.02%
Employed, working part-time	12.24%
Not employed, looking for work	0.00%
Not employed, not looking for work	10.20%
Retired	16.33%
Disabled, not able to work	10.20%

Figure 3: “Question 3: Which of the Following Best Describes your Employment Status?”

QUESTION 4: “IF YOU LIVE IN CANADA, IN WHAT PROVINCE/TERRITORY DO YOU RESIDE?”

This question ascertains which Canadian Province or Territory participants from Canada reside in. The available options were “British Columbia,” “Alberta,” “Saskatchewan,” “Manitoba,” “Ontario,” “Québec,” “New Brunswick,” “Nova Scotia,” “Newfoundland & Labrador,” “Prince Edward Island,” and “Yukon/Northwest Territory/ Nunavut.”

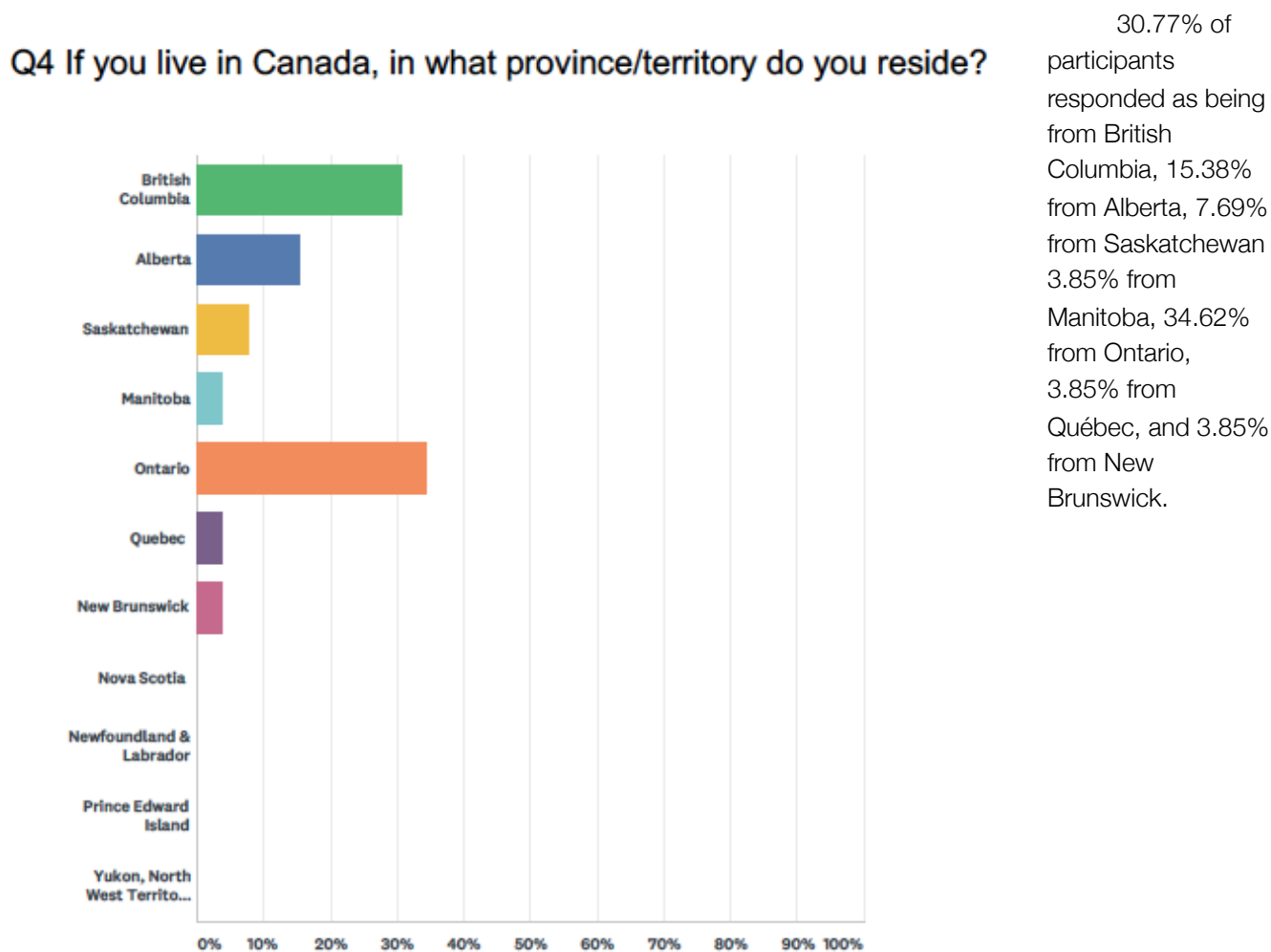


Figure 4: “Question 4: If you Live in Canada, in what Province/Territory do you Reside?”

QUESTION 5: “IF YOU DO NOT LIVE IN CANADA, IN WHAT COUNTRY DO YOU RESIDE?”

Question 5 identifies where survey participants are from, if not Canada.

The vast majority (80.00%) of participants identified as being from the United States of America, while the remainder were from either Australia or New Zealand.

QUESTION 6: “IN WHAT YEAR WERE YOU FIRST DIAGNOSED WITH MELANOMA?”

Question 6 assesses what year each participant was initially diagnosed with melanoma.

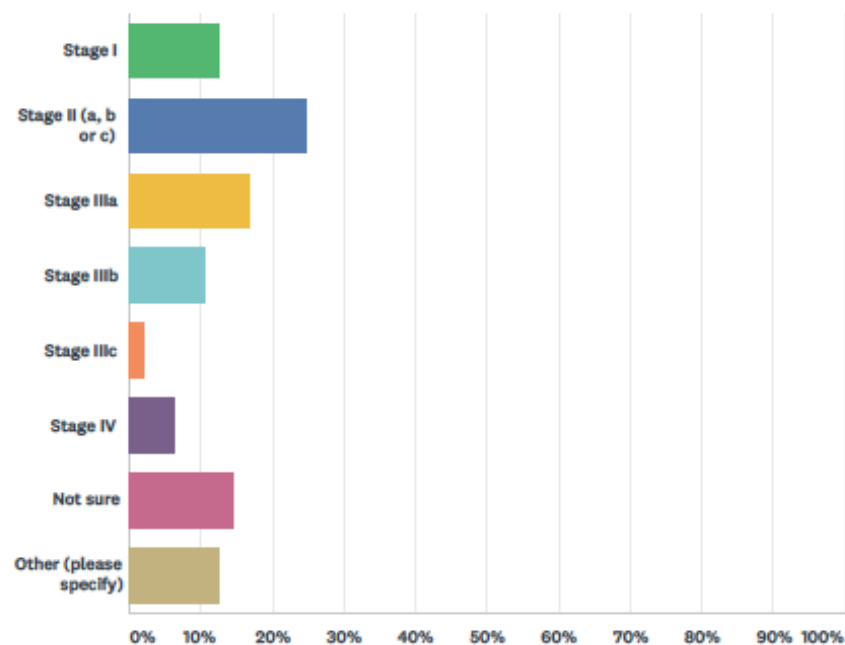
Responses ranged from 1991-2018. Working backwards from the majority, the responses were distributed as follows: 6 participants were diagnosed in 2013, 2016, 2017; 4 were diagnosed in both 2012 and 2018; 3 were diagnosed in 2007, 2014, and 2015; 2 were diagnosed in 2009 and 2011; and one was diagnosed in 1991, 2003, 2008, and 2010.

QUESTION 7: “AT WHAT STAGE WAS YOUR FIRST DIAGNOSIS OF MELANOMA?”

Question 7 ascertains what stage of melanoma each survey participant was at when they were diagnosed. The available responses were “stage I;” “stage II (a, b, or c);” “stage IIIa;” “stage IIIb;” “stage IIIc,” “stage IV;” “not sure;” and “other,” which allowed participants to fill in their own responses.

12.50% of participants reported being at stage I when they were diagnosed, 25.00% at stage II (a, b, or c), 16.67% at stage IIIa, 10.42% at stage IIIb, 2.08% at stage IIIc, 6.25% at stage IV, 14.58% were unsure, and 12.50% participants wrote in their own responses under the ‘other’ category. Of these responses, 3 reported that their melanoma was stage 0, 1 that their melanoma was unstaged, 1 that their melanoma was in situ, and 1 that their stage was retroactively determined to be II.

Q7 At what stage was your first diagnosis of melanoma?



ANSWER CHOICES	RESPONSES
Stage I	12.50%
Stage II (a, b or c)	25.00%
Stage IIIa	16.67%
Stage IIIb	10.42%
Stage IIIc	2.08%
Stage IV	6.25%
Not sure	14.58%
Other (please specify)	12.50%

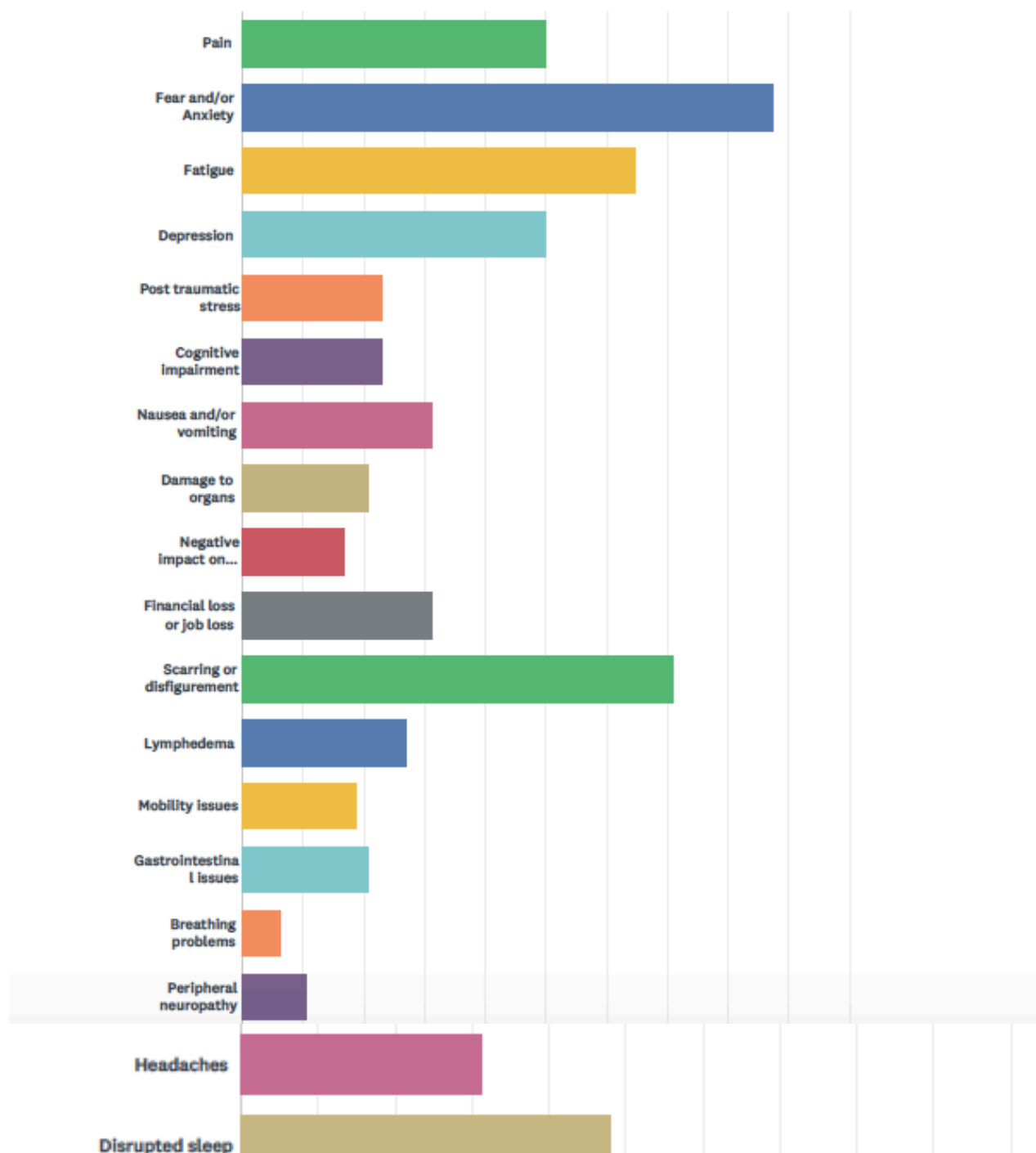
Figure 5: “Question 7: At what Stage was your First Diagnosis of Melanoma?”

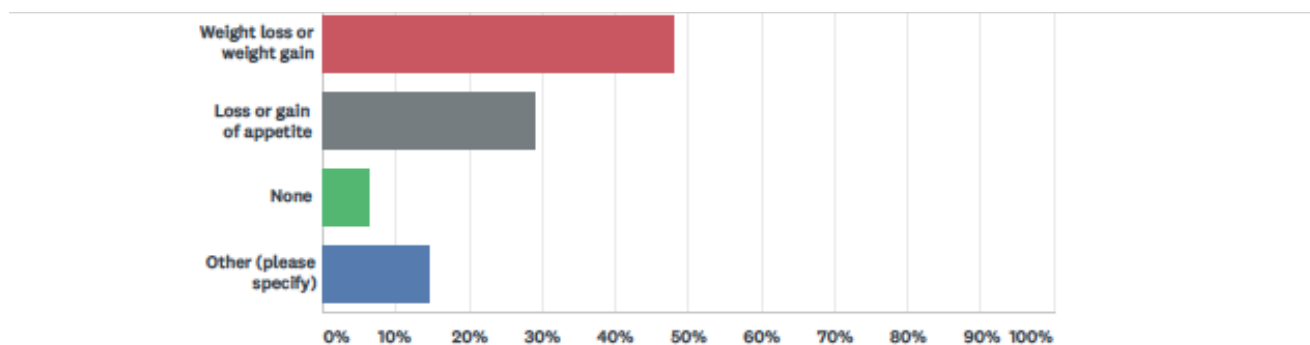
QUESTION 8: "CANCER, AND THE VARIOUS STAGES OF CANCER, AFFECT PEOPLE IN DIFFERENT WAYS. WHAT ISSUES HAVE YOU EXPERIENCED WITH MELANOMA? PLEASE SELECT AS MANY RESPONSES AS APPROPRIATE."

This question gauges which, if any, side effects survey participants have experienced as a result of their melanoma diagnosis and/or treatments. The patients could select as many responses from the list below that they felt applied to them, and had the option to fill in 'other' side effects missing from the list. The options on the list were "pain," "fear and/or anxiety," "fatigue," "depression," "post traumatic stress," "cognitive impairment," "nausea and/or vomiting," "damage to organs," "negative impact on relationships," "financial loss or job loss," "scarring or disfigurement," "lymphedema," "mobility issues," "gastrointestinal issues," "breathing problems," "peripheral neuropathy," "headaches," "disrupted sleep," "weight loss or weight gain," "loss or gain of appetite," "none," and "other," in which participants had the option to write in their own responses.

Working backwards from the majority, 87.50% of participants reported experiencing fear and/or anxiety as a side effect of their melanoma diagnosis, 70.83% reported scarring or disfigurement, 64.58% reported fatigue 50.00% reported pain, 50.00% reported depression, 47.92% reported disrupted sleep, 47.92% reported weight loss or weight gain, 31.25% reported financial loss or job loss, 31.25% reported headaches, 29.17% reported loss or gain of appetite, 27.08% reported lymphedema, 22.92% reported post traumatic stress, 22.92% reported cognitive impairment, 20.83% reported damage to organs, 18.75% reported mobility issues, 16.67% reported a negative impact on their relationships, 10.42% reported peripheral neuropathy, 6.25% reported breathing problems, and 6.25% reported that they had no side effects. 14.58% of participants responded with 'other' and filled in a side effect. One response specified that their side effects were from their treatment and surgery; one listed hair thinning; one listed heart toxicity from treatment, thyroid loss, pituitary shot, Bell's palsy, and adrenal insufficiency; one listed loss of bladder function; one listed lymphatic chording; and one listed low sodium and a body rash.

Q8 Cancer, and the various stages of cancer, affect people in different ways. What issues have you experienced with melanoma? Please select as many responses as appropriate.





ANSWER CHOICES	RESPONSES
Pain	50.00%
Fear and/or Anxiety	87.50%
Fatigue	64.58%
Depression	50.00%
Post traumatic stress	22.92%
Cognitive impairment	22.92%
Nausea and/or vomiting	31.25%
Damage to organs	20.83%
Negative impact on relationships	16.67%
Financial loss or job loss	31.25%
Scarring or disfigurement	70.83%
Lymphedema	27.08%
Mobility issues	18.75%
Gastrointestinal issues	20.83%
Breathing problems	6.25%
Peripheral neuropathy	10.42%
Headaches	31.25%
Disrupted sleep	47.92%
Weight loss or weight gain	47.92%
Loss or gain of appetite	29.17%
None	6.25%
Other (please specify)	14.58%

Figure 6: “Question 8: Cancer, and the Various Stages of Cancer, Affect People in Different Ways. What Issues have you Experienced with Melanoma? Please Select as Many Responses as Appropriate.”

QUESTION 9: “IN RELATION TO THE SYMPTOMS YOU HAVE INDICATED ABOVE, HOW DID OR DO THESE SYMPTOMS AFFECT YOUR DAY TO DAY LIFE? WHAT, IF ANY, PROBLEMS HAVE AFFECTED YOUR LIFE OR QUALITY OF LIFE AS A RESULT OF HAVING MELANOMA?”

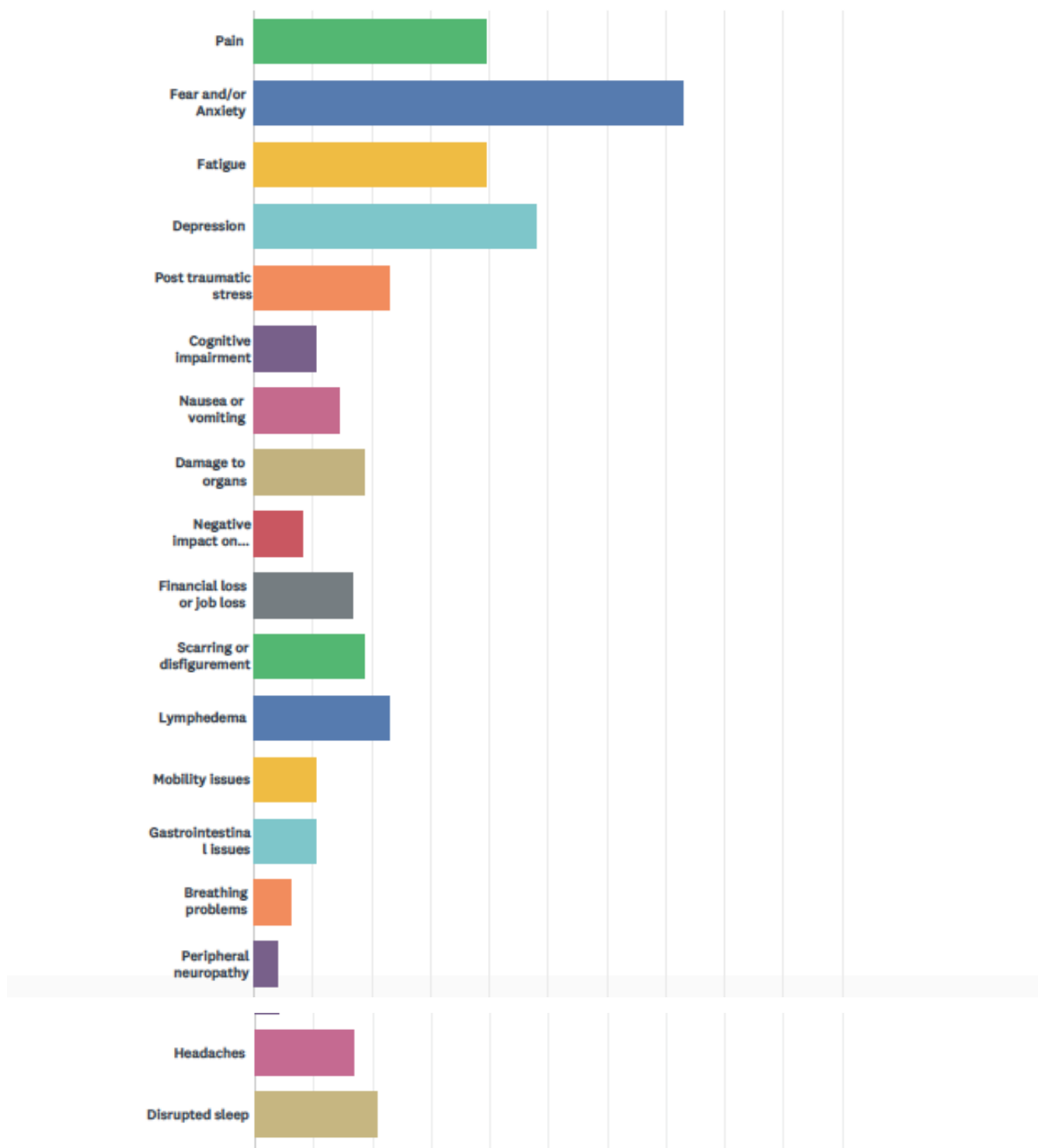
This question allowed participants to fill in their own responses, and indicate how their lives have changed as a result of their melanoma diagnosis. In situations wherein participants listed more than one effect, both effects were recorded independently.

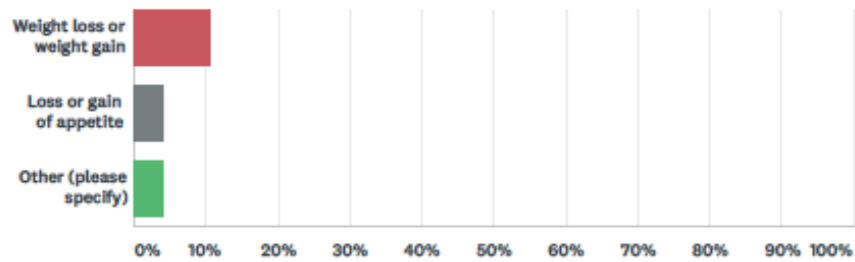
9 participants wrote that they experienced a peak in anxiety around their follow-up tests, and when they contemplated the possibility of recurrence. Anxiety was mentioned by an additional 9 participants. Several (6) participants mentioned fatigue, and many mentioned that due to a combination of fatigue and anxiety, they are either unable to work, causing financial issues (8), or are having difficulty maintaining their social life (5). Other responses mentioned ongoing pain or other damage caused by treatment (6), depression (3) and insecurity due to scarring (3). 2 participants mentioned that they are unsure of how to plan for the future, and participants also mentioned ongoing nausea (1), lymphedema (1), heart toxicity (1), and post traumatic stress (1). Several participants mentioned that these symptoms affected their ability to spend time with their children and grandchildren, and that they felt unable to relate to their friends as they could before their diagnosis. One participant mentioned feelings of guilt for their sun exposure before diagnosis, and another suggested that because melanoma is not a well-known cancer, they felt that people around them minimized their experiences.

QUESTION 10: “IN YOUR OPINION, WHICH SYMPTOMS OF THE DISEASE ARE [THE] MOST IMPORTANT TO CONTROL?”

Question 10 asks survey participants which symptoms of melanoma (as listed above) they felt were the most important to control. Participants had the option to select as many options as they wished. The options on the list were “pain,” “fear and/or anxiety,” “fatigue,” “depression,” “post traumatic stress,” “cognitive impairment,” “nausea and/or vomiting,” “damage to organs,” “negative impact on relationships,” “financial loss or job loss,” “scarring or disfigurement,” “lymphedema,” “mobility issues,” “gastrointestinal issues,” “breathing problems,” “peripheral neuropathy,” “headaches,” “disrupted sleep,” “weight loss or weight gain,” “loss or gain of appetite,” “none,” and “other,” in which participants had the option to write in their own responses.

Q10 In your opinion, which symptoms of the disease are most important to control?





ANSWER CHOICES	RESPONSES
Pain	39.58%
Fear and/or Anxiety	72.92%
Fatigue	39.58%
Depression	47.92%
Post traumatic stress	22.92%
Cognitive impairment	10.42%
Nausea or vomiting	14.58%
Damage to organs	18.75%
Negative impact on relationships	8.33%
Financial loss or job loss	16.67%
Scarring or disfigurement	18.75%
Lymphedema	22.92%
Mobility issues	10.42%
Gastrointestinal issues	10.42%
Breathing problems	6.25%
Peripheral neuropathy	4.17%
Headaches	16.67%
Disrupted sleep	20.83%
Weight loss or weight gain	10.42%
Loss or gain of appetite	4.17%
Other (please specify)	4.17%

Figure 7: “Question 10: In your Opinion, which Symptoms of the Disease are the Most Important to Control?”

There were 2 responses in the ‘other’ section, both of which suggested that all of the side effects were equally important, and that their prominence shifted throughout the treatment cycle. Working backwards from the majority, 72.92% of participants suggested that fear and/or anxiety was the most important side effect to control,

47.92% said it was depression, 39.58% said it was pain, 39.58% said it was fatigue, 22.92% said it was post traumatic stress, 22.92% said it was lymphedema, 20.83% said it was disrupted sleep, 18.75% said it was damage to organs, 18.75% said it was scarring or disfigurement, 16.67% said it was financial loss or job loss, 16.67% said it was headaches, 14.58% said it was nausea or vomiting, 10.42% said it was cognitive impairment, 10.42% said it was mobility issues, 10.42% said it was gastrointestinal issues, 10.42% said it was weight loss or weight gain, 8.33% said it was the negative impact that diagnosis had on their relationships, 6.25% said it was breathing problems, 4.17% said it was peripheral neuropathy, and 4.17% said it was loss or gain of appetite. While the previous two questions in this survey have demonstrated that ongoing health complications and financial loss are a profound issue for patients, they rank below fear and/or anxiety and depression as side effects that patients require greater support when experiencing. This emphasizes the need for mental wellness support for melanoma (and all cancer) patients, survivors, and their caregivers.

QUESTION 11: “HOW HAS RECEIVING A MELANOMA DIAGNOSIS AFFECTED YOUR FAMILY OR PRIMARY CAREGIVER? WHAT CHALLENGES, IF ANY, HAS YOUR SPOUSE OR PARTNER, OTHER CAREGIVER, OR FAMILY MEMBER EXPERIENCED THAT MAY HAVE IMPACTED THEIR DAY TO DAY LIFE?”

Question 11 assesses the affect that participant’s melanoma diagnosis may have had on the people around them, such as their spouse and other members of their family, or their primary caregiver. Participants were given the opportunity to write in their own responses. In situations wherein participants listed more than one effect, both effects were recorded independently.

The majority of responses (14) suggested that the lifestyle of the participant’s spouse or partner has been impaired by the melanoma diagnosis in some way. This includes having to change their schedule to make appointments and take care of the spouse with melanoma, and not being able to maintain their friendships. Often, participants suggested that their caregivers were exhausted with the efforts of being a caregiver, while continuing to work and manage the household. Caregivers often have to miss work or lose their jobs due to their new responsibilities, and 9 responses suggested that their family has incurred financial difficulties, whether it is through the loss of an income, both incomes in the case that their partner misses work or loses their job, or the cost of care. Many participants (8) mentioned that their partners or spouses were in constant fear of their melanoma recurring, or of their death, a fear that often extended to their children when this was applicable. A few (7) participants mentioned that the mental wellness of their family had suffered, including both their partner and their children, when applicable. 2 participants mentioned that their family was unsure of what the next moves to make were, in both life and in the case of their cancer treatments, and 2 more said that they spent effort trying to put on a brave face for their partner, to take some weight off their shoulders.

The aforementioned responses largely indicate relationships that stayed positive and supportive throughout participant’s melanoma journey, but responses indicate that this was not always the case. 1 participant

suggested that the adjustments made to their lifestyle was partially responsible for their divorce. 4 participants indicated that their melanoma caused strain on their relationship, or that it was difficult for them to find support in their partner. 2 mentioned that they felt unable to communicate their experiences to their partner.

While the changes in lifestyle due to a melanoma diagnosis appear to be overwhelmingly negative for both the patient and their caregiver, some participants tried to suggest silver linings to the experience. 3 comments said that their diagnosis had no effect on their caregiver, and 2 comments suggested that the experience brought their family closer together. 2 other comments stated other positives to the experience, such as being more aware of the dangers of UV exposure, and their children being inspired to go into the medical field.

QUESTION 12: “WHAT DOES YOUR SPOUSE OR PARTNER, FAMILY MEMBER, AND/OR CAREGIVER SAY ABOUT THE IMPACT OF MELANOMA ON THEIR DAILY LIFE? HAS IT HAD AN IMPACT (POSITIVE OR NEGATIVE) ON THEM?”

The next question asks for caregiver perspectives on how their lives have changed due to the participant's melanoma diagnosis. Participants were asked to write in their own responses. In situations wherein participants listed more than one effect, both effects were recorded independently.

Responses to this question were overwhelmingly negative, with 18 participants simply stating that the impact of their melanoma diagnosis on their caregiver has been negative. Some participants went into further detail: 5 noted that their family or caregiver experience increased anxiety around their scans, 5 suggest that their caregiver has felt especially financially strained due to the melanoma, 1 suggested that their partner feels isolated and unable to relate to other people, and 1 mentioned that her partner did not pursue a university education in order to keep their insurance. 3 participants noted that as much as their partner tries to appear unfazed, they know it weighs on them.

However, there were a surprising number of positive responses (9) to this question. Reasons for positive responses include that the participant's family has grown closer together, that they no longer take anything for granted, and that they are much more aware of the dangers of UV exposure.

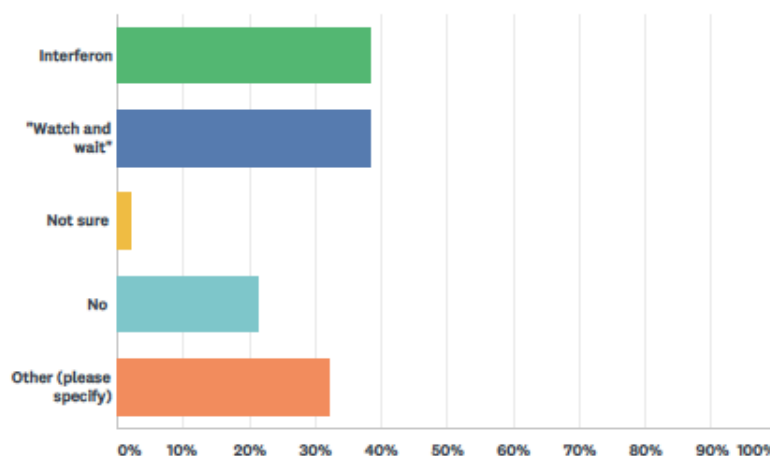
5 responses were neutral, with 4 caregivers reporting that the melanoma diagnosis has had no impact on their lives, and 1 survey participant stating that their partner ignores the disease as much as possible.

QUESTION 13: “WAS ANY TREATMENT OFFERED TO YOU IN THE ADJUVANT SETTING?”

The next question ascertains whether treatment in the adjuvant setting has ever been offered to survey participants. The available options were “interferon,” “watch and wait,” “not sure,” “no,” and “other,” where participants had the option of writing in a response.

38.30% of participants selected interferon, 38.30% selected “watch and wait,” 2.13% selected not sure, 21.28% selected no, and 31.91% participants selected other and filled in a response. 3 of these responses reiterated that they had not been offered treatment in the adjuvant setting. 3 participants wrote that they participated in an unspecified clinical trial, while 4 mentioned specific trials including opdivo, ipilimumab, and IL 2.

Q13 Was any treatment offered to you in the adjuvant setting?



ANSWER CHOICES	RESPONSES
Interferon	38.30%
"Watch and wait"	38.30%
Not sure	2.13%
No	21.28%
Other (please specify)	31.91%

Figure 8: “Question 13: Was any Treatment Offered to you in the Adjuvant Setting?”

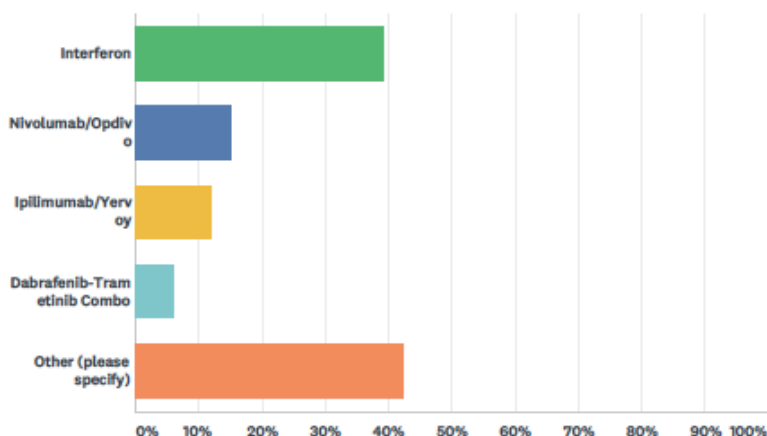
QUESTION 14: “IN THE ADJUVANT SETTING, WERE YOU TREATED WITH ANY DRUG THERAPY FOR YOUR MELANOMA? SELECT ALL THAT APPLY.”

This question assesses what treatments survey participants have received in the adjuvant setting. Participants were invited to select as many available options as applied to them from “interferon,” “nivolumab/opdivo,” “ipilimumab/yervoy,” “the dabrafenib-trametinib combo,” and “other,” wherein they had the option to fill in their own responses.

39.39% of participants selected interferon, 15.15% selected nivolumab/opdivo, 12.12% selected ipilimumab/yervoy, 6.06% selected the dabrafenib-trametinib combo, and 42.42% selected ‘other’ and filled in

their own responses. Of these responses, 11 participants stated that they had been treated with none of the listed options. 1 participant reported being given a high dose IL 2, one an ipilimumab trial, and 1 an opdivo-yervoy combination followed by opdivo for maintenance.

Q14 In the adjuvant setting, were you treated with any drug therapy for your melanoma? Select all that apply.



ANSWER CHOICES	RESPONSES
Interferon	39.39%
Nivolumab/Opdivo	15.15%
Ipilimumab/Yervoy	12.12%
Dabrafenib-Trametinib Combo	6.06%
Total Respondents: 33	

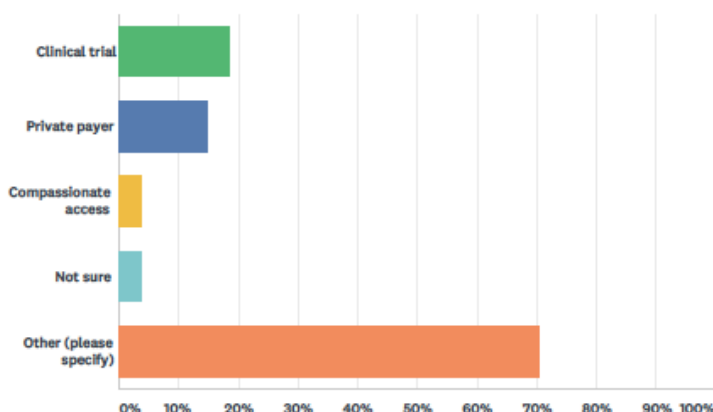
Figure 9: “Question 14: In the Adjuvant Setting, were you Treated with any Drug Therapy for your Melanoma? Select all that Apply”

QUESTION 15: “IF YOU RECEIVED DRUG THERAPY, HOW DID YOU OBTAIN THIS TREATMENT?”

Question 15 enquires as to how participants obtained any drug therapies they may have received. The available options were “clinical trial,” “private payer,” “compassionate access,” “not sure,” and “other,” wherein patients had the option to fill in their own responses.

18.52% of participants selected clinical trial, 14.81% selected private payer, 3.70% selected compassionate access, 3.70% selected not sure, and 70.37% selected ‘other’ and wrote in their responses. Of

Q15 If you received drug therapy, how did you obtain this treatment?



ANSWER CHOICES	RESPONSES
Clinical trial	18.52%
Private payer	14.81%
Compassionate access	3.70%
Not sure	3.70%

Total Respondents: 27

these responses, 5 participants reiterated that the question was not applicable to them. Of the responses that specifically addressed how their treatment was accessed, 7 participants noted that they had some variety of insurance. 2 were not specified, 1 cited a special access program through Health Canada, 2 suggested provincial or government insurance, and 2 were covered by private insurance.

Figure 10: “Question 15: If you Received Drug Therapy, how did you Obtain this Treatment?”

QUESTION 16: “IF YOU WERE NOT ABLE TO RECEIVE ANY DRUG THERAPY IN THE ADJUVANT SETTING AND WERE TOLD TO ‘WATCH AND WAIT’ TO SEE IF THE DISEASE WOULD PROGRESS, WHAT WOULD HAVING ACCESS TO NEW DRUG THERAPIES MEAN TO YOU?”

Question 16 allows participants to fill in responses describing what having access to innovative care would mean to survey participants. In situations wherein participants listed more than one effect, both effects were recorded independently.

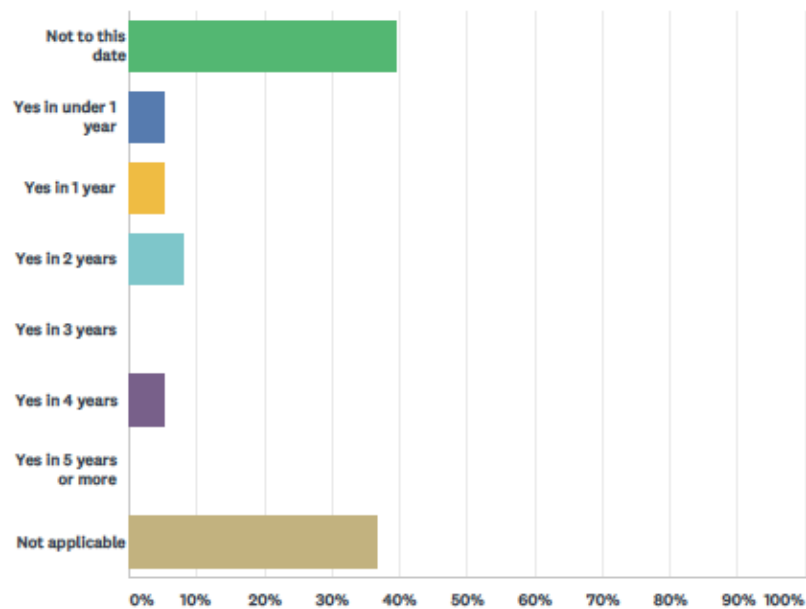
Six participants suggested the question was not applicable to them. The majority of patients expressed excitement at an increase in treatment options, which were phrased in a variety of ways. The most common response (9 participants) was that new treatments would be everything, equatable to life itself. The word “everything” itself appeared multiple times, and several participants wrote responses to a similar effect. One participant wrote that new therapies “would have meant the world to [them]! [They] would have been a game changer,” while another wrote “It would mean saving a human life. It would mean [the] ability to see grandchildren growing up. It would mean [the] end of despair and hope for [the] future.” Other reoccurring themes within the responses that desired more treatment options included suggestions that they would have felt more secure if they had more options (6), and 6 more participants felt that their melanoma would not have progressed to a higher stage with a different treatment, or that maintenance treatment would help prevent recurrence. Overall, this question seemed to have the most uniform responses so far; aside from the small portion of patients that did not feel this question applied to them, every other response suggested enthusiasm for new treatment possibilities, including many responses that implied a new treatment would be the best thing they could hope for.

QUESTION 17: “IF YOU RECEIVED NO DRUG THERAPY AND REMAINED ON ‘WATCH AND WAIT,’ DID YOUR MELANOMA PROGRESS?”

This question ascertains whether the participants that had not received adjuvant therapy also experienced a progression of their melanoma. The available responses were “not to this date,” “yes, in under 1 year,” “yes, in 1 year,” “yes, in 2 years,” “yes, in 3 years,” “yes, in 4 years,” “yes, in 5 years or more,” and “not applicable.”

39.47% of participants had no melanoma progression to date, 5.26% saw progression in under a year, 5.26% saw progression at the year mark, 7.89% saw progression at the two year mark, 0.00% saw progression at the 3 year mark, 5.26% saw progression at the 4 year mark, 0.00% saw progression at the 5 year mark, and 36.84% responded that the question was not applicable to them.

**Q17 If you received no drug therapy and remained on “watch and wait,”
did your melanoma progress?**



ANSWER CHOICES	RESPONSES
Not to this date	39.47%
Yes in under 1 year	5.26%
Yes in 1 year	5.26%
Yes in 2 years	7.89%
Yes in 3 years	0.00%
Yes in 4 years	5.26%
Yes in 5 years or more	0.00%
Not applicable	36.84%

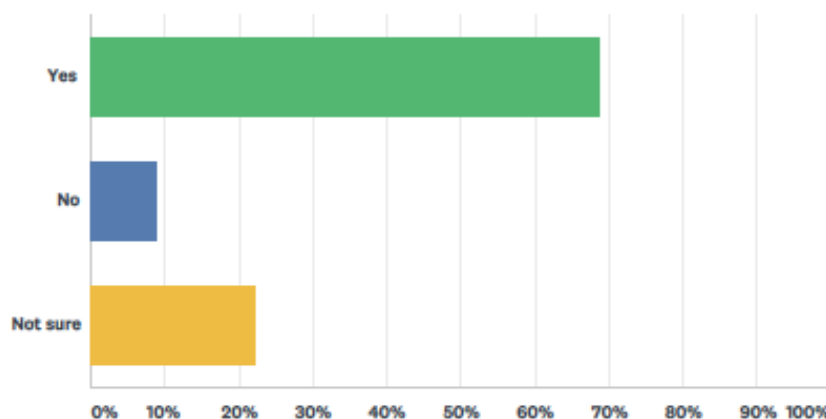
Figure 11: “Question 17: If you Received No Drug Therapy and Remained on “Watch and Wait,” did your Melanoma Progress?”

QUESTION 18: “IF YOU WERE OFFERED A DRUG THERAPY ON A CLINICAL TRIAL, WOULD YOU CONSIDER TAKING IT?”

Question 18 gauges the participants’ interest in a hypothetical clinical trial. The available options were “yes,” “no,” and “not sure.”

68.89% of participants stated that they would consider a clinical trial if it was offered to them. This was the majority for this question. 8.89% of participants stated that they would not consider a clinical trial, and 22.22% of participants were not sure.

Q18 If you were to be offered a drug therapy on a clinical trial, would you consider taking it?



ANSWER CHOICES	RESPONSES
Yes	68.89%
No	8.89%
Not sure	22.22%

Figure 12: “Question 18: If you were to be Offered a Drug Therapy on a Clinical Trial, would you Consider taking it?”

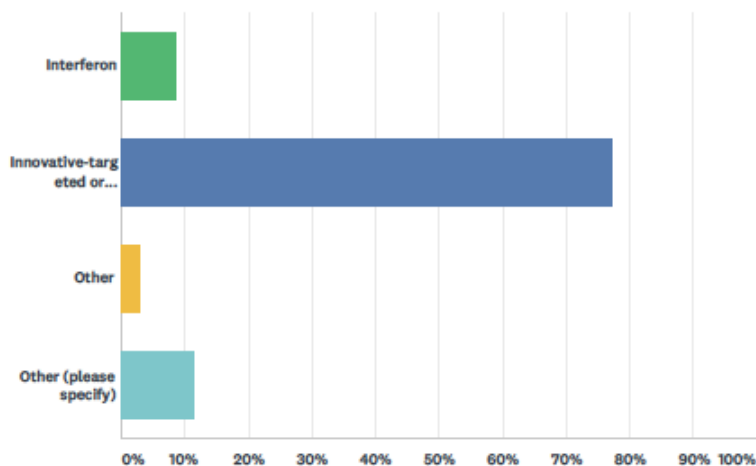
QUESTION 19: “IF YOU WERE NOT ABLE TO RECEIVE ANY DRUG THERAPY BUT WISH YOU COULD, WHAT WOULD YOU CHOOSE?”

This question asks participants what drug therapy they would be interested in, if they could choose one. The available options were “interferon,” “innovative-targeted or immuno-oncology,” “other,” and “other (please specify),” in which participants had the option to write their own responses.

8.57% of participants stated that they would prefer interferon, 77.14% that they would prefer innovative-targeted or immuno-oncology, 2.86% participant selected other, and 11.43% selected other please specify. One

response stated that the question was not applicable to them; one mentioned that their doctor recommended immunotherapy; one stated that they would try anything offered; and one stated that after participating in the Oncovex trial they would be interested in pursuing another oncolytic virus therapy.

Q19 If you were not able to receive any drug therapy but wish you could, what would you choose?



ANSWER CHOICES	RESPONSES
Interferon	8.57%
Innovative-targeted or immuno-oncology	77.14%
Other	2.86%
TOTAL	

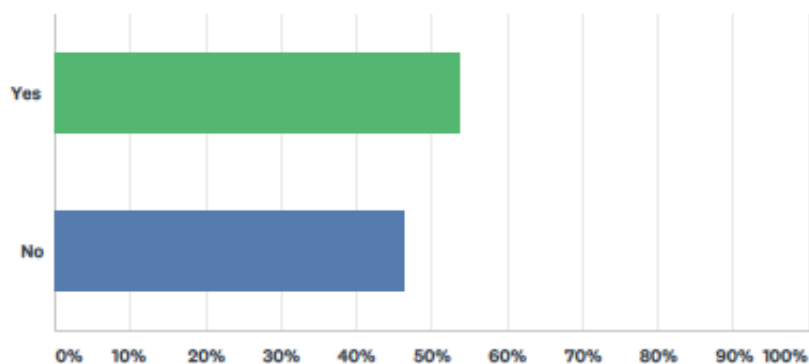
Figure 13: “Question 19: If you were not able to Receive any Drug Therapy but Wish you could, what would you Choose?”

QUESTION 20: “DID YOU COMPLETE [YOUR] FULL COURSE OF TREATMENT? IF NOT, PLEASE EXPLAIN WHY.”

This question ascertains whether participants had completed the full course of their treatment. The available options were “yes,” or “no,” however patients had the option to comment and elaborate on their experience.

53.85% of participants responded that yes, they had completed their full course of treatment. 46.15% responded that they had been unable to complete their full course of treatment. There were 20 comments for this question. 8 participants responded that they were unable to complete their treatment due to side effects or other complications, and 2 indicated that their disease progressed and they were unable to continue treatment. 4 participants responded that there were no treatments available to them. 2 participants were still in treatment at the time of the survey. 2 participants reiterated that they had completed their treatment, and 2 stated that the question was not applicable to them.

Q20 Did you complete the full course of treatment? If not, please explain why.

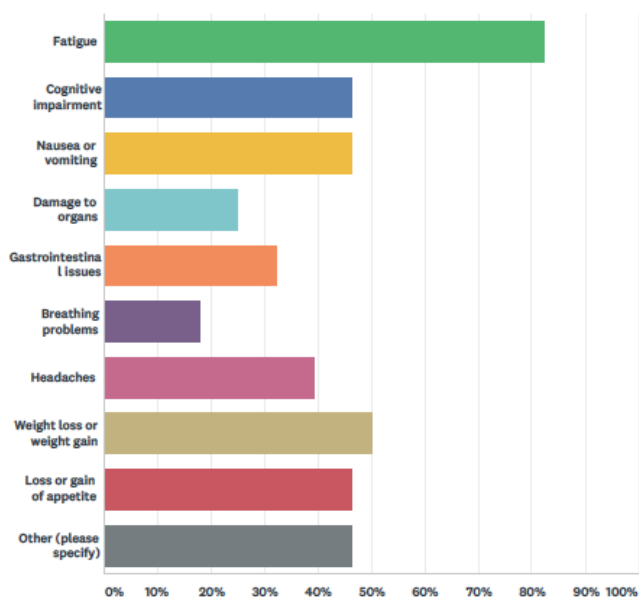


ANSWER CHOICES	RESPONSES
Yes	53.85%
No	46.15%

Figure 13: “Question 20: Did you Complete the Full Course of Treatment? If Not, Please Explain Why.”

QUESTION 21: “WHAT (IF ANY) SIDE EFFECTS DID YOU EXPERIENCE FROM THIS TREATMENT? SELECT ALL THAT APPLY.”

**Q21 What (if any) side effects did you experience from this treatment?
(select all that apply)**



Question 21 determines which side effects were experienced by the survey participants during their treatments. Participants were invited to select however many options applied to them, and had the opportunity to provide additional answers. The available answers were “fatigue,” “cognitive impairment,” “nausea or vomiting,” “damage to organs,” “gastrointestinal issues,” “breathing problems,” “headaches,” “weight loss or weight gain,” “loss or gain of appetite,” and “other,” in which participants could write in their own responses.

ANSWER CHOICES	RESPONSES
Fatigue	82.14%
Cognitive impairment	46.43%
Nausea or vomiting	46.43%
Damage to organs	25.00%
Gastrointestinal issues	32.14%
Breathing problems	17.86%
Headaches	39.29%
Weight loss or weight gain	50.00%
Loss or gain of appetite	46.43%
Other (please specify)	46.43%

Figure 14: “Question Twenty-One: What (if any) Side Effects did you Experience from this Treatment? (Check all that Apply).”

82.14% of participants reported that they experienced fatigue, 46.43% cognitive impairment, 46.43% nausea or vomiting, 25.00% damage to organs, 32.14% gastrointestinal issues, 17.86% breathing problems, 39.29% headaches, 50.00% weight loss or weight gain, 46.43% loss or gain of appetite, and 46.43% selected 'other' and filled in a side effect. Five of these responses stated that the question was not applicable to them, 2 because they had not undergone treatment and 3 because they experienced no side effects. Depression, anxiety, and rashes were each mentioned by 2 participants. Several other side effects were mentioned once, including hair thinning, bell's palsy, thyroid issues, pituitary and adrenal insufficiency, cardio myopathy, cardiac issues, flu-like symptoms, joint discomfort, and vitiligo.

QUESTION 22: "WERE THE SIDE EFFECTS MANAGEABLE?"

This question allows survey participants to plot their side effects on a scale, from 1, meaning not manageable, to 5, meaning yes.

The weighted average was 3.16, with 12.00% of participants responding that their side effects were at 1 on the scale, so not manageable; 16.00% put their side effects at 2 on the scale, so slightly more manageable; 36.00% put their side effects at 3; 16.00% put their side effects at 4; and 20.00% put their side effect at 5 on the scale, meaning they found that their side effects were manageable.

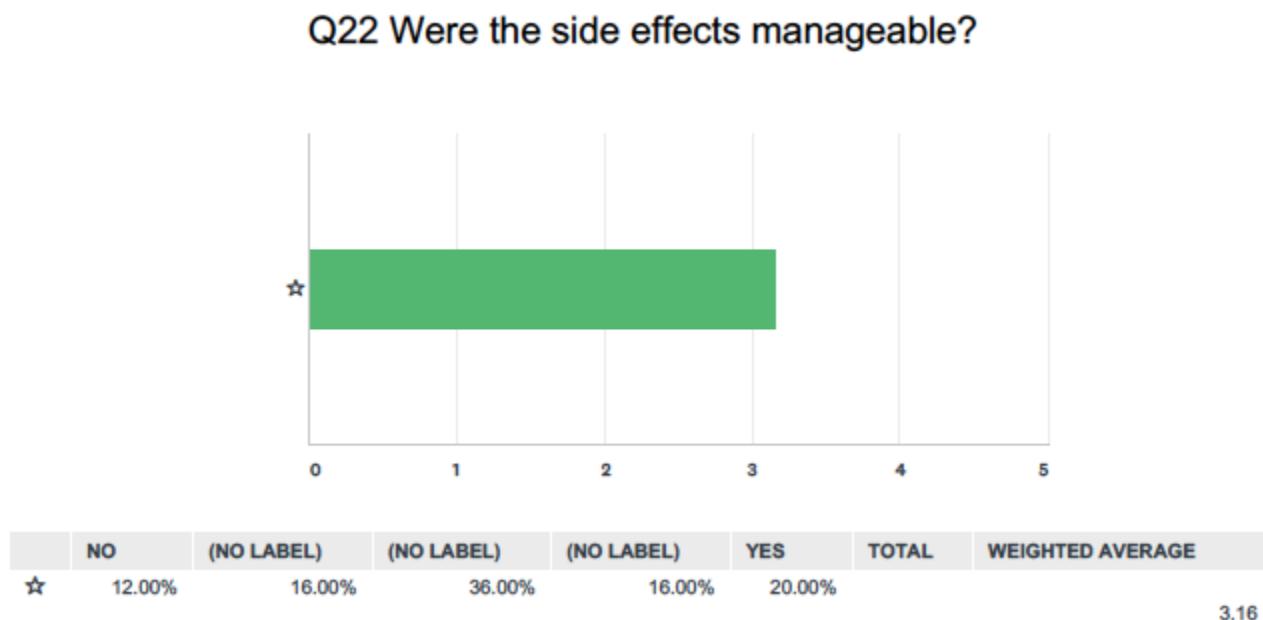


Figure 15: "Question Twenty-Two: Were the Side Effects Manageable?"

QUESTION 23: “IF YOU HAD A FULL RESPONSE TO YOUR TREATMENT, HOW LONG HAS IT BEEN SINCE YOU HAD YOUR LAST TREATMENT?”

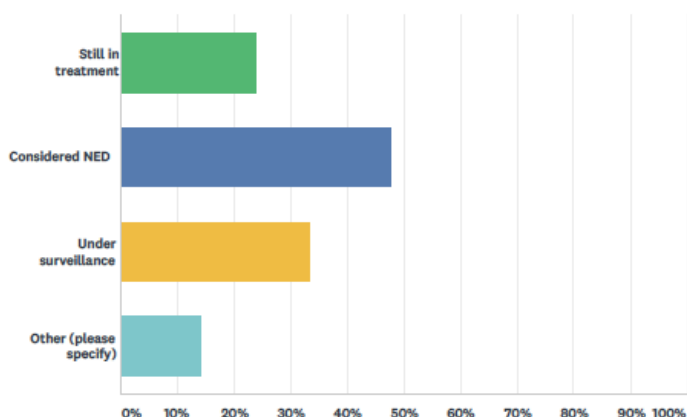
Question 23 ascertains when the survey participants have their most recent treatments.

3 responses suggested that the question was not applicable to them. 2 participants had their most recent treatment within one year from the survey date in 2018; 6 participants had their most treatment within five years from that date; 3 within ten years from that date; and 3 within fifteen years from that date.

QUESTION 24: “WHAT IS THE CURRENT STATE OF YOUR MELANOMA DISEASE?”

This question gauges the current status of the survey participants’ melanoma. The available answers for participants to choose from were “still in treatment,” “considered NED,” “under surveillance,” and “other,” wherein participants had the option to write in their own responses.

Q24 What is the current status of your melanoma disease?



23.81% of participants were still in treatment at the time of the survey in 2018. 47.62% were considered NED at that time. 33.33% were under surveillance, and 14.29% responded with ‘other’ and wrote in their own response. Of these responses, two reiterated that they are considered NED.

ANSWER CHOICES	RESPONSES
Still in treatment	23.81%
Considered NED	47.62%
Under surveillance	33.33%
Total Respondents: 42	

Figure 16: “Question Twenty-Four: What is the Current Status of your Melanoma Disease?”

QUESTION 25: “IF YOU EXPERIENCED SIDE EFFECTS FROM A DRUG THERAPY, DID THE BENEFITS OF THE TREATMENT OUTWEIGH THE EXPERIENCE OF THE SIDE EFFECTS?”

This question asks participants whether they felt that whichever treatment they had outweighed the side effects they experienced. The available answers were “yes,” “no,” “not sure,” and “not applicable.”

51.52% of participants answered yes, 9.09% answered no, 15.15% answered not sure, 24.24% answered not applicable.

Q25 If you experienced side effects from a drug therapy, did the benefits of the treatment outweigh the experience of the side effects?

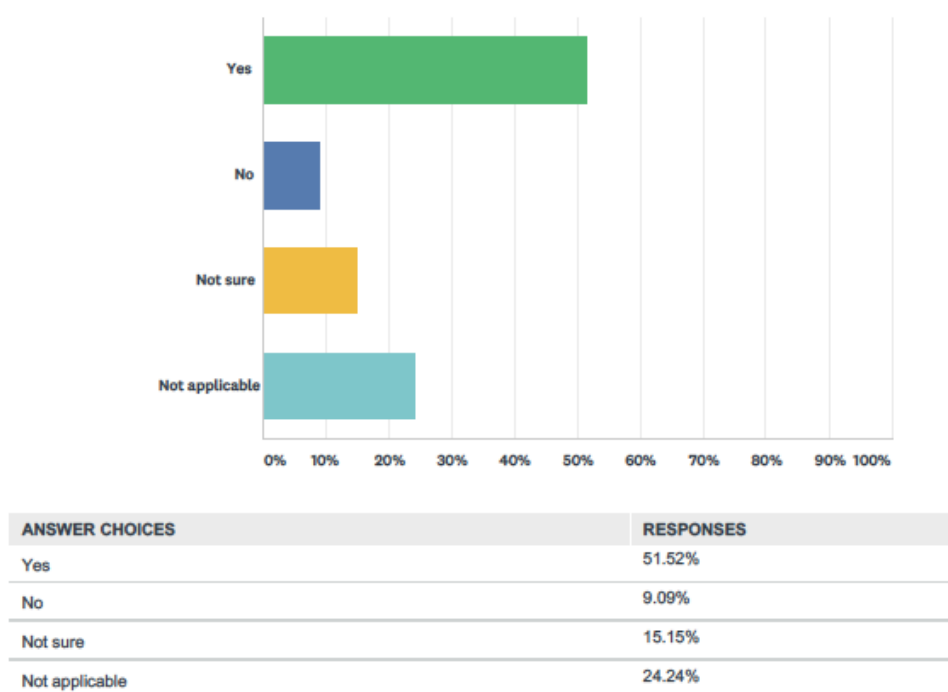


Figure 17: “Question Twenty-Five: If you Experienced Side Effects from a Drug Therapy, did the Benefits of the Treatment Outweigh the Experience of the Side Effects?”

QUESTION 26: “DID YOU EXPERIENCE ANY HARDSHIPS THAT BARRED YOU FROM ACCESSING 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.”

Question 26 ascertains what hardships survey participants had encountered in their attempts to access treatment. Participants were asked to write in their own responses. In situations wherein participants listed more than one hardship, both hardships were recorded independently.

Of these responses, 10 participants reiterated that this question was not applicable to them. Based on the responses, the most common hardships encountered by patients were having to travel to access care (5), the complete inability to access necessary care (5), and financial difficulty of paying for care (3).

QUESTION 27: “WHAT ARE IMPORTANT VALUES TO YOU WHEN HEARING OF OR TRYING A NEW TREATMENT[,] EG. QUALITY OF LIFE, ABILITY TO PERFORM DAILY ACTIVITIES, RETURN TO WORK/ABILITY TO REMAIN AT WORK, NO SIDE EFFECTS, ETC.”

For question 27, participants were asked to list what the most important aspects are to them when considering a potential new treatment. Participants were invited to write in their own responses. In situations wherein participants listed more than one factor, both factors were recorded independently.

The overwhelming response was quality of life, which was suggested by 23 participants. For the purposes of the survey, we combined responses that specifically said the phrase ‘quality of life’ with responses that suggested a desire to return to normalcy. The next most common responses, both of which were mentioned by 10 participants, were efficacy and management of side effects. 2 participants cited affordability, and 1 mentioned convenience. While the affordability and convenience were not mentioned often, the responses to question 26 suggest that financial difficulty and having to travel become a hardship when treatment is actually accessed.

QUESTION 28: “IF YOU COULD DESCRIBE WHAT YOU AS A PATIENT ARE LOOKING FOR IN NEW TREATMENTS COMING TO THE MARKET, WHAT WOULD YOU SAY?”

This question ascertains what survey participants are looking for in new treatments coming to the market. Participants were asked to write in their responses. In situations wherein participants listed more than one factor, both factors were recorded independently.

Unsurprisingly, the majority of participants (18) cited efficacy as their primary concern when considering new treatments. Efficacy, here, refers to both the speed of the treatment and long-term survival. Minimal side effects was considered the next most important factor, cited by 14 participants, and quality of life was mentioned by 4. Factors that were listed by two or fewer participants include affordability, insurance coverage, minimal effects on fertility, convenience, safety, evidence-based data, and minimally invasive.

CONCLUSION

The results of this survey illuminated several aspects of the melanoma patient treatment experience, including the frequency and management of side effects (question 21, 22), access to treatment (question 13, 14, 15), and what kinds of treatment survey participants would be interested in and whether they would be interested in taking it as a clinical trial (question 19, 18). However, the results also emphasized the affective experiences of melanoma patients, specifically what kind of hardships a melanoma diagnosis and treatment can introduce into a patient's life (question 26), how a melanoma diagnosis can affect the patient's family (question 11, 12), and the feelings that patients have toward the possibility of new treatments (question 16).

Question 26, regarding the hardships that survey participants have undergone through their melanoma treatments, listed the lack of access to care, having to travel for care, and financial affordability. Question 26 is the only question in this survey that explicitly considers access to care, aside from the responses to question 28 ("if you could describe what you as a patient are looking for in new treatments...") that intuited that access may be an issue for incoming treatments. Access to care is an ongoing issue, that is contributed to by a number of factors, including the mobility and financial hardships that were mentioned frequently in question 26. Mobility issues most often affect patients that do not live in a major city, and therefore have to travel to receive their treatments. Mobility often affects financial hardship, because in addition to paying for however much of their treatments, patients who need to travel for treatments often have to incur additional travel and accommodation costs.

How a melanoma diagnosis affects the patient's family, partner, and/or caregiver were explored in questions 11 and 12. The response to the questions "how has receiving a melanoma diagnosis affected your family or primary caregiver? What challenges, if any, has your spouse or partner, other caregiver, or family member experienced that may have impacted their day to day life?" and Question 12: "what does your spouse or partner, family member, and/or caregiver say about the Impact of melanoma on their daily life? Has it had an impact (positive or negative) on them?" did have some positive responses or 'silver linings,' but were largely negative. Many of these responses suggested that their partner was overwhelmed by having to take on the role of caregiver, while continuing to work and manage the household. In more extreme cases, participants reported that their partners lost their jobs due to the additional stress, adding financial difficulty; some responses also suggested that melanoma made them and their partner put plans on hold, or resulted in divorce.

Question 16, which asked what a new treatment option would mean to participants, generated an overall enthusiastic response. Many participants suggested that a new treatment option would mean something along the

lines of “everything,” or “life itself.” Others mentioned that they would feel more secure if they had more treatment options available, in case they have to change their treatment plan. Some participants stated that if they believe their melanoma would not have progressed to the next stage if they had more treatment options. Overall, the participants that responded to the question seemed to regard more treatment options as an important hope for them to have.

Overall, it is clear that the melanoma participants in this survey are active participants in their care and are invested in cancer care, as they were willing to take the time to participate in this survey. While treatments are emerging that offer a good quality of life, many melanoma patients, along with their partners and caregivers, still have a difficult time leading a normal life during their treatments, and additional pressure often falls on patient’s partner to both be a caregiver and run the household. Further, while new medications are rapidly becoming available, factors such as financial barriers, mobility, and lack of access mean that more treatment options are needed to help patients navigate these burdens. Patients are anxiously awaiting treatments that offer a good quality of life and long-term survival rates, while being affordable and accessible.