



Save Your Skin Foundation
July 29, 2018

Save Your Skin Foundation 2018 Ocular Melanoma Survey Report

From February 2, 2018- July 10, 2018, the Canadian Melanoma patient group Save Your Skin Foundation ran the survey “Save Your Skin Foundation Patient Survey: Understanding Ocular Melanoma in Canada,” which assessed the experiences of Canadian patients with ocular melanoma, their care plans, and their opinions of the ocular melanoma treatment landscape. The survey was run through the SurveyMonkey platform, and consisted of a mixture of multiple choice and short-answer questions. There were eighteen (18) questions in total, one of which includes confidential contact information of participants and will therefore not be shared in this report. Each question allowed participants the opportunity to comment, should they feel the need to elaborate on their experiences. The platform also offered the option for participants to skip questions. This result will be based on the responses of 27 participants, which is the total number of Canadian participants in the survey.

The following report is based entirely on the results of the “Understanding Ocular Melanoma in Canada” survey. Results that are deemed not relevant to the report, including the responses from participants from outside of Canada, will be excluded (seven (7) participants). For access to the original survey data, contact the Save Your Skin Foundation. The opinions professed in this document do not represent those of the Save Your Skin Foundation, and are amalgamations of the feedback received in the patient survey only.

Uveal, or ocular, melanoma makes up approximately 5% of melanomas, and has a 50% metastatic recurrence rate at 15 years. It is generally resistant to systemic treatment, though the continuous development of precision medicines may improve the prognosis for those diagnosed. The median progression-free survival of metastatic uveal melanoma is 1.5-3 months, and the median survival is 8-12 months (Leyvraz et al).

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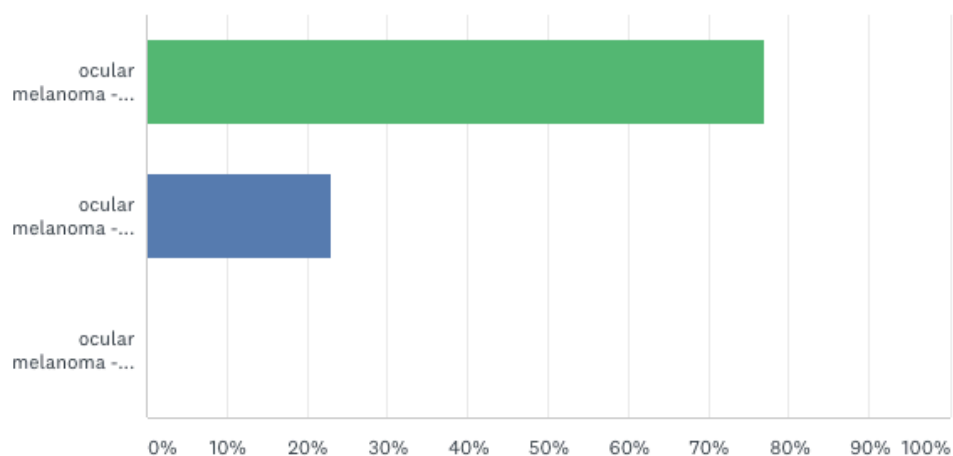
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Question One (1): Type of Ocular Melanoma

The first question (1) of the survey asked participants what form of ocular melanoma they were initially diagnosed with. Twenty-six (26) survey participants answered this question, and it was skipped by one (1) participant. The potential responses were “ocular melanoma - primary,” “ocular melanoma - metastatic,” and “ocular melanoma - other.”

Were you diagnosed with:

Answered: 26 Skipped: 1



| ANSWER CHOICES | RESPONSES |
|------------------------------|-----------|
| ocular melanoma - primary | 76.92% 20 |
| ocular melanoma - metastatic | 23.08% 6 |
| ocular melanoma - other | 0.00% 0 |
| TOTAL | 26 |

Figure 1: Responses to Question One (1)

The percentage breakdown is as follows (fig.1, above):

Ocular melanoma - primary: 76.92% (20)
 Ocular melanoma - metastatic: 23.08% (6)
 Ocular melanoma - other: 0.00% (0)

There were four (4) comments on this question. Two of which specified their diagnosis further, with one patient having choroidal melanoma and another ciliary body melanoma. One comment suggested that this participant was unsure of what form of ocular melanoma they have, and that they did not feel their condition was adequately explained by their doctor.

Question Two (2): “In What Year Were you First Diagnosed, whether Primary or Metastatic?”

Question two (2) allowed participants to write in the year they were initially diagnosed with ocular melanoma, whether it was primary or metastatic. Twenty-seven (27) participants answered this question, and it was skipped by zero (0) participants.

The response breakdown is as follows, listing only years that were cited in the survey:

2018: one participant (1)
2017: eight participants (8)
2016: three participants (3)
2014: five participants (5)
2013: one participant (1)
2012: one participant (1)
2011: one participant (1)
2010: two participants (2)
2009: one participant (1)
2008: one participant (1)
2004: two participants (2)
1977: one participant (1)

There were no comments affiliated with this question.

Question Three (3): “If you have had Recurrence of this Disease, in what Year did this Occur?”

Question three (3) allowed participants to write in responses. Twenty-two (22) participants answered this question, and it was skipped by five (5) participants.

The response breakdown was as follows:

2018: five participants (5)
2017: one participant (1)
2014: one participant (1)
2013: one participant (1)

2012: one participant (1)
 2011: one participant (1)
 1998: one participant (1)
 N/A: eleven participants (11)

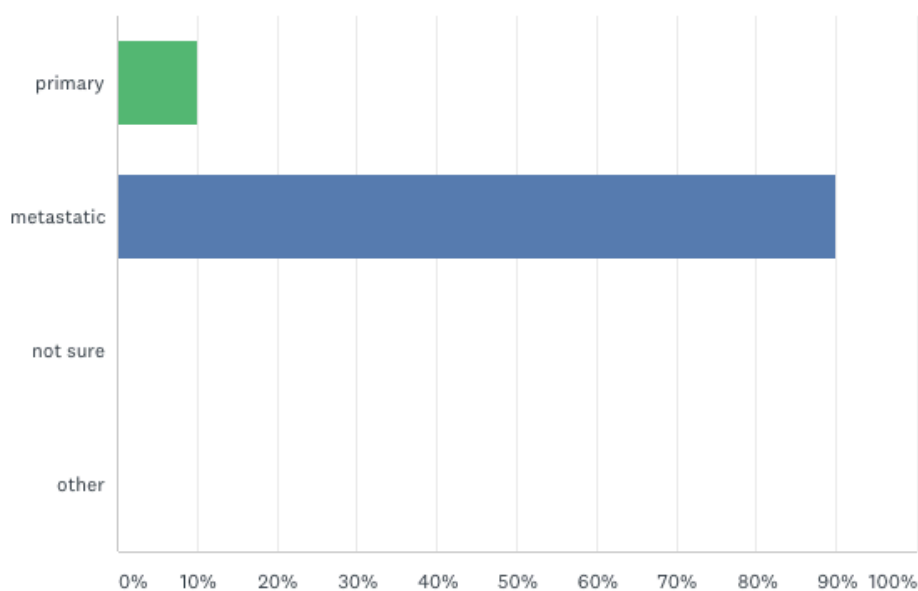
There were no comments affiliated with this question.

Question four (4): Recurrence of Disease

Question four (4) asked participants whether their recurrence of ocular melanoma was primary or metastatic, if they had recurrence. This question was answered by ten (10) participants and skipped by seventeen (17) participants. The response options were “primary,” “metastatic,” “not sure,” and “other.”

If you have had recurrence of disease, was it:

Answered: 10 Skipped: 17



| ANSWER CHOICES | RESPONSES |
|----------------|-----------|
| primary | 10.00% 1 |
| metastatic | 90.00% 9 |
| not sure | 0.00% 0 |
| other | 0.00% 0 |
| TOTAL | 10 |

Figure 2: Responses to Question Four (4)

The percentage breakdown is as follows (fig. 2, above):

Primary: 10.00% (1)
Metastatic: 90.00% (9)
Not sure: 0.00% (0)
Other: 0.00% (0)

There were ten comments on this question. While the majority of these (8) reiterated that this question was not applicable to them, one commenter noted that their recurrence seemed to be a breakout from the original cancer site, and was more aggressive than their original tumour.

Question Five 5: “For Confirmation of Ocular Melanoma Metastasis, have you had a Biopsy?”

Question Five (5) ascertained whether participants had received biopsies to confirm their ocular melanoma metastasis. Twenty-one (21) participants answered this question, and it was skipped by six (6) participants. The available options were “yes, for monosomy 3,” “yes, for gene expression profiling,” “no,” and “not sure.”

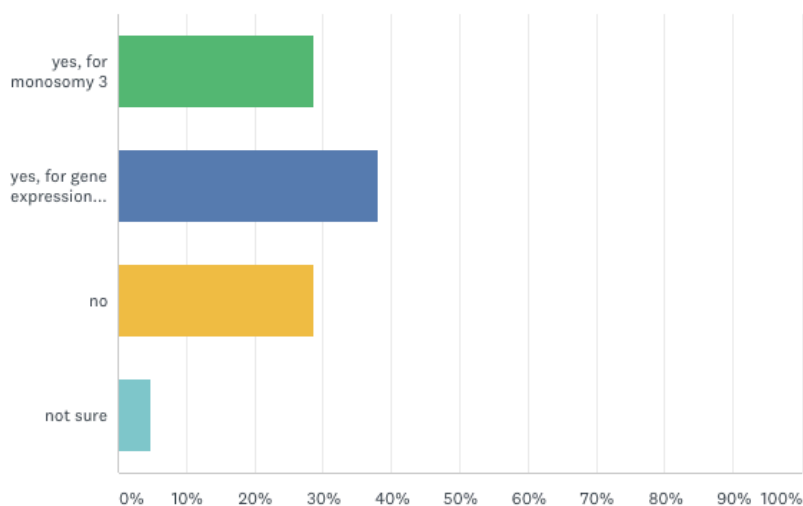
The response breakdown was as follows (fig. 3, below):

Yes, for monosomy 3: 28.57% (6)
Yes, for gene expression profiling: 38.10% (8)
No: 28.57% (6)
Not sure: 4.76% (1)

Of the six comment responses, three noted that the question was not applicable to them, as they had not had metastasis. One response stated that they had received CT and MRI scans in place of a biopsy. One response stated that they had expressed interest in a biopsy, but were told by their doctor that they were not a candidate.

For confirmation of ocular melanoma metastasis, have you had a biopsy?

Answered: 21 Skipped: 6



| ANSWER CHOICES | RESPONSES | |
|--------------------------------------|-----------|-----------|
| ▼ yes, for monosomy 3 | 28.57% | 6 |
| ▼ yes, for gene expression profiling | 38.10% | 8 |
| ▼ no | 28.57% | 6 |
| ▼ not sure | 4.76% | 1 |
| TOTAL | | 21 |

Figure 3: Responses to Question Five (5)

Question Six (6): “If you have had a Biopsy, has the Information from it had any Implications on your Follow-Up Plan?”

Question Six (6), which enquired about the implications of a patient’s biopsy on their follow-up care plan, was answered by eighteen (18) participants and skipped by nine (9) participants. The available answers were “yes,” “no,” and “unsure.”

The percentage breakdown was as follows (figure 4, below):

Yes: 61.11% (11)

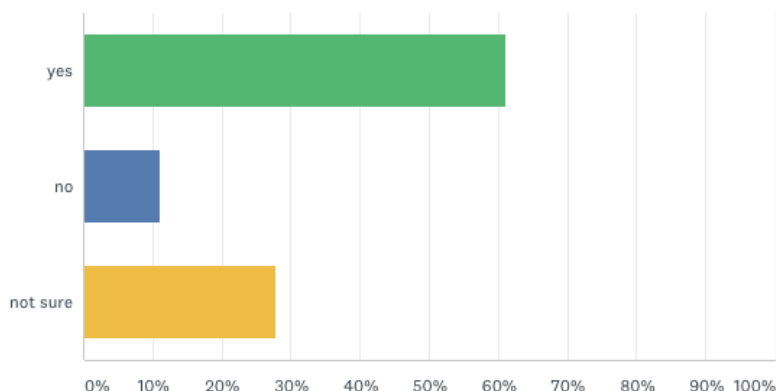
No: 11.11% (2)

Not sure: 27.78% (5)

Of the eight (8) comments, five (5) confirmed that the question was not applicable to them, while three (3) included more details about their increased follow-up plan.

If you have had a biopsy, has the information from it had any implications on your follow-up plan?

Answered: 18 Skipped: 9



| ANSWER CHOICES | RESPONSES |
|----------------|-----------|
| yes | 61.11% 11 |
| no | 11.11% 2 |
| not sure | 27.78% 5 |
| TOTAL | 18 |

Figure 4: Responses to Question Six (6)

Question Seven (7): “Have you Ever had Treatment for Ocular Melanoma?”

Question seven (7), which allowed participants to select multiple responses that applied to them, ascertained what treatments survey participants had undergone for ocular melanoma. This question was answered by twenty-seven (27) survey participants, and skipped by zero (0) participants. The available answers were “surgery,” “brachytherapy,” “proton beam radiation,” “chemotherapy,” “immunotherapy,” “not sure,” and “other.” Patients were asked, if possible, to further elaborate on the responses of “chemotherapy,” “immunotherapy,” and “other.”

The percentage breakdown was as follows (figure 5, below):

Surgery: 33.33% (9)
 Brachytherapy: 74.07% (20)
 Proton beam radiation: 3.70% (1)

Chemotherapy: 3.70% (1)
Immunotherapy: 22.22% (6)
Not sure: 0.00% (0)
Other: 23.93% (7)

There were seven (7) comments associated with this question, in which participants cited the treatments selumetinib (an ATP-independent inhibitor), avastin (a biotherapy), and keytruda (an anti-PD-1 immunotherapy) as treatments they had undergone.

Have you ever had treatment for ocular melanoma? (check all that apply)

Answered: 27 Skipped: 0

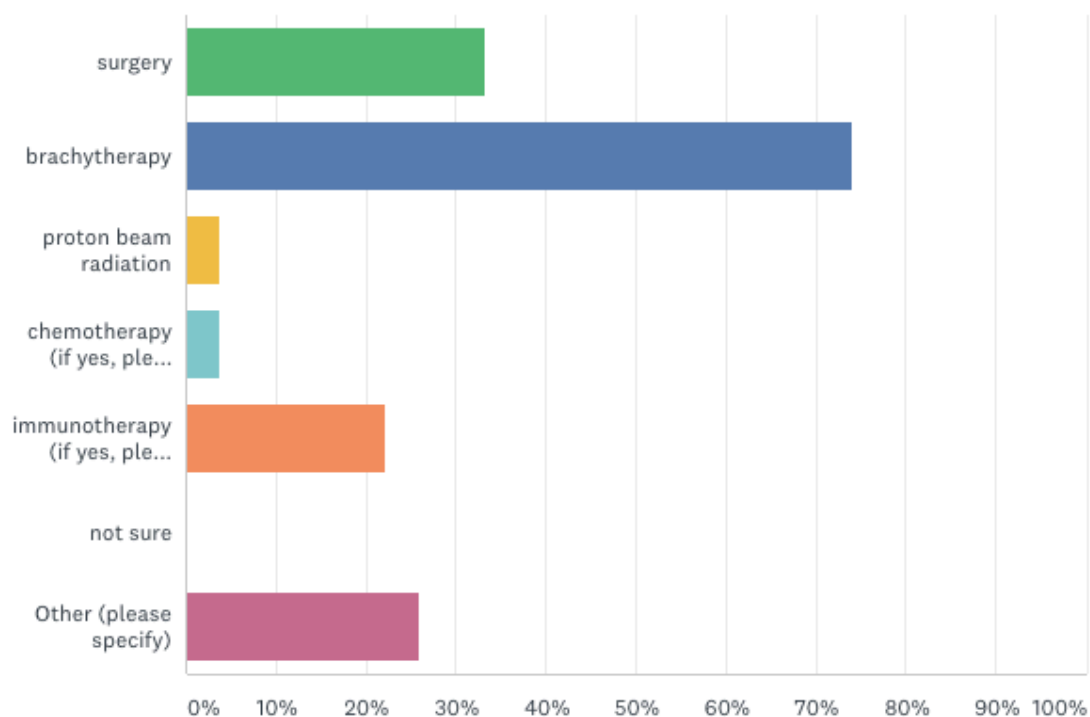


Figure 5: Responses for Question Seven (7)

Question Eight (8): When was your Most Recent Treatment for Ocular Melanoma?”

Question eight (8), which ascertained the most recent treatment survey participants had undergone for their ocular melanoma, was answered by twenty-seven (27) survey participants, and skipped by zero (0) survey participants. Participants were able to write in their own responses to the question.

The responses were as follows, excluding responses that did not include a date:

2018: Six (6) participants
2017: Seven (7) participants
2016: Two (2) participants
2015: Two (2) participants
2014: Two (2) participants
2013: One (1) participant
2012: One (1) participant
2011: One (1) participant
2004: One (1) participant
2000: One (1) participant

Question Nine (9): “In What Country do you Live?”

Question nine (9) confirmed that the survey participants are current residents of Canada. In order to keep the survey results accurate, participants who professed to not be Canadian at this stage were excluded from the survey, leaving the twenty-seven participants whose experiences have been used to assemble this report.

Question Ten (10): “If you Live in Canada, in Which Province do you Live?”

In response to question ten (10), participants had the opportunity to state which Canadian province they reside in. This question was answered by twenty-seven (27) participants, and skipped by zero (0) participants.

The results were as follows:

British Columbia: six participants (6)
Ontario: ten participants (10)
Québec: two participants (2)
Alberta: six participants (6)
Saskatchewan: two participants (2)
Newfoundland: one participant (1)

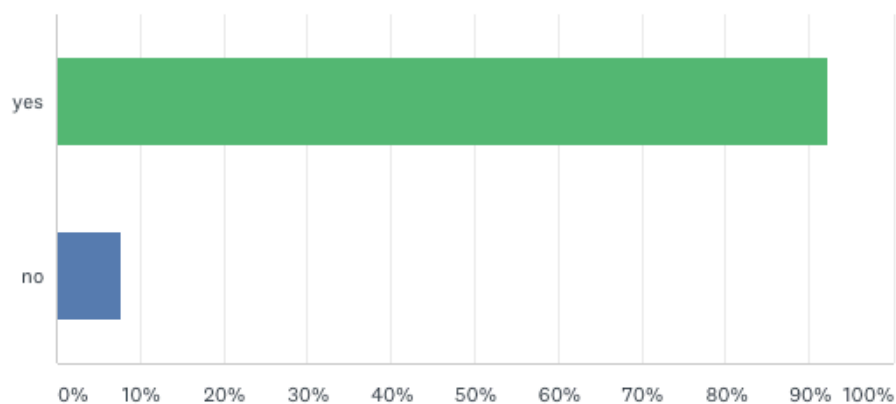
There were no comments associated with this question.

Question Eleven (11): “Do you Live in the Same Province as when you were Diagnosed with Ocular Melanoma?”

Question eleven (11) gauged whether patients current live in the same province as they did when they were diagnosed with melanoma. This question was answered by twenty-six (26) survey participants, and skipped by one (1) survey participant. The available answers were “yes” or “no.”

Do you live in the same province as when you were diagnosed with ocular melanoma?

Answered: 26 Skipped: 1



| ANSWER CHOICES | RESPONSES | |
|----------------|-----------|-----------|
| ▼ yes | 92.31% | 24 |
| ▼ no | 7.69% | 2 |
| TOTAL | | 26 |

Figure 6: Responses to Question Eleven (11).

The response breakdown was as follows (fig. 6, above):

Yes: 92.31% (24)

No: 7.69% (2)

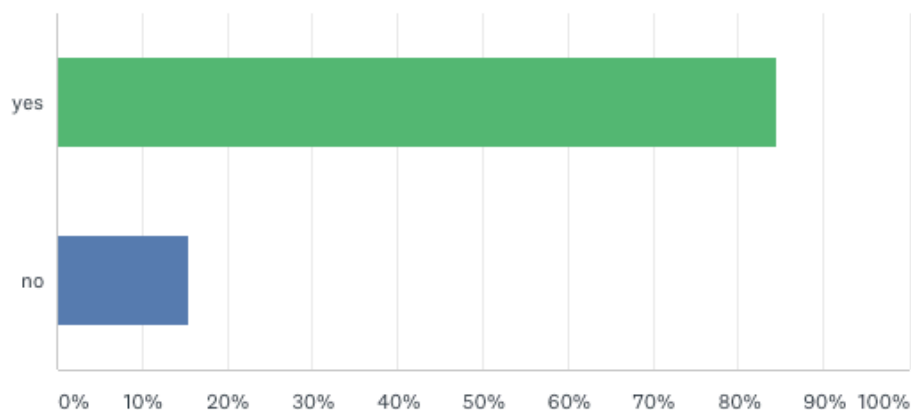
There were no comments affiliated with this question.

Question Twelve (12): “If you Received Treatment for Ocular Melanoma, was it in the Same Province as the One where you Lived at the Time of Treatment?”

Question Twelve (12) ascertained whether survey participants had received treatments for ocular melanoma in the same province they had lived in at the time of their diagnosis. Twenty-six (26) survey participants answered this question, and one (1) participant skipped the question. The possible answers were “yes” or “no.”

If you received treatment for ocular melanoma, was it in the same province as the one where you lived at the time of treatment?

Answered: 26 Skipped: 1



| ANSWER CHOICES | RESPONSES | |
|----------------|-----------|-----------|
| ▼ yes | 84.62% | 22 |
| ▼ no | 15.38% | 4 |
| TOTAL | | 26 |

Figure 7: Responses to Question Twelve (12).

The response breakdown was as follows (fig. 7, above):

Yes: 84.26% (22)

No: 15.38% (4)

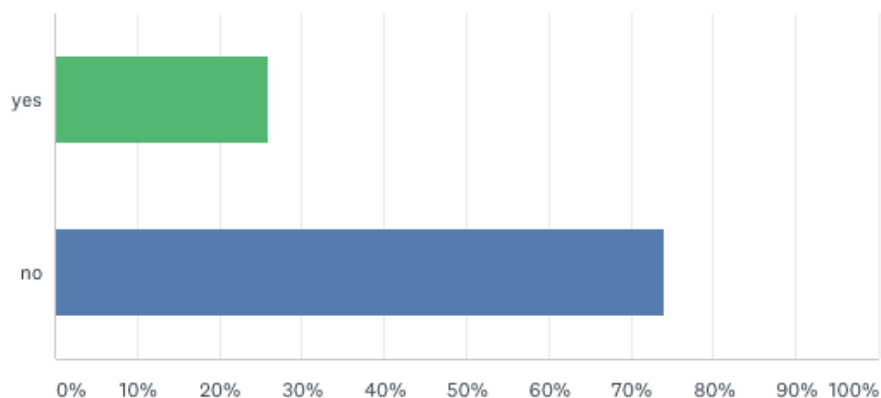
There were no comments affiliated with this question.

Question Thirteen (13): “Has your Medical Team Ever Referred you to an Oncologist in Another Province?”

Elaborating on question twelve (12), question thirteen (13) asks participants whether they have ever been referred to an oncologist in a province outside their province of residence. This question was answered by twenty-seven (27) participants, and skipped by zero participants (0). The possible answers were “yes” and “no.”

Has your medical team ever referred you to an oncologist in another province?

Answered: 27 Skipped: 0



| ANSWER CHOICES | RESPONSES | |
|----------------|-----------|-----------|
| ▼ yes | 25.93% | 7 |
| ▼ no | 74.07% | 20 |
| TOTAL | | 27 |

Figure 8: Responses to Question Thirteen (13).

The response breakdown was as follows (fig. 8):

Yes: 25.93% (7)
 No: 74.07% (20)

There were ten comment responses to this question. Of these comments, five (5) stated that they had been treated within their province. One responder (1) did not recollect ever having been referred to an oncologist. One (1) participant, who is from Saskatchewan, wrote that they were treated and followed in Ontario, and two (2) participants, both from Ontario, were referred to clinical trials in Philadelphia.

Question Fourteen (14): “Do you or did you have Educational Materials or Informative Support at your Cancer Centre Specifically Related to Ocular Melanoma?”

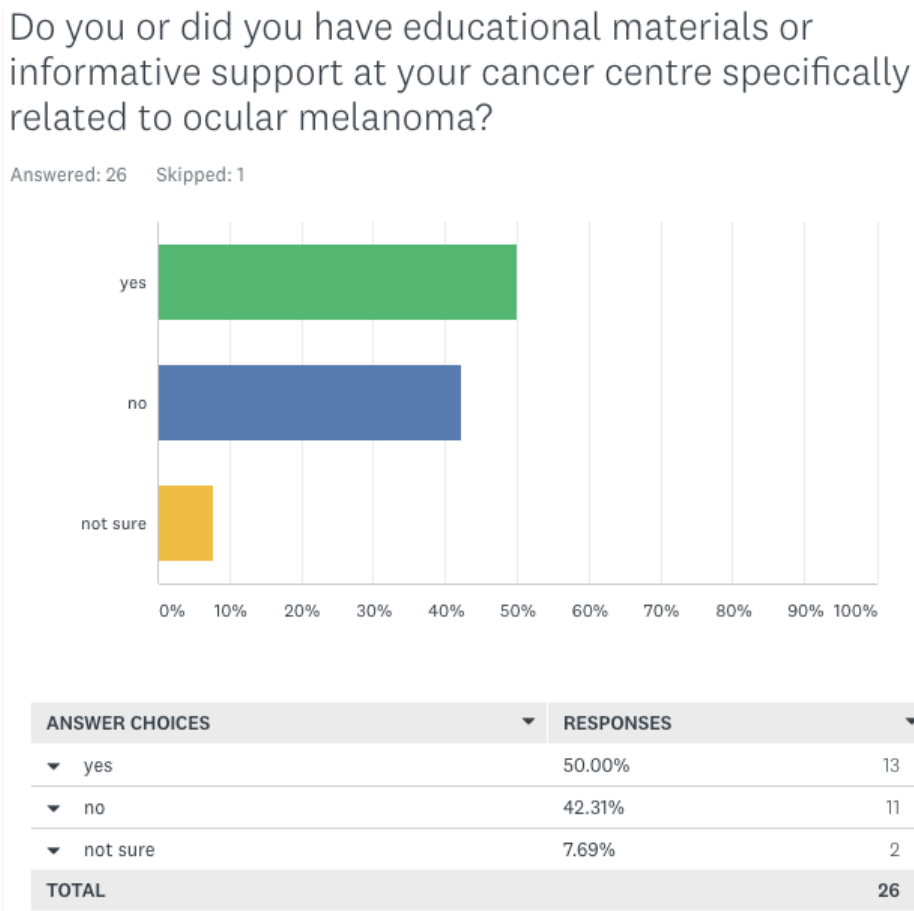


Figure 9: Responses to Question Fourteen (14)

Question Fourteen (14) sought to ascertain the availability of ocular melanoma-specific resources at the medical facilities participants were treated at. Twenty-six participants (26) responded to this question, and it was skipped by one (1) participant. The possible answers were “yes,” “no,” and “not sure.”

The response breakdown was as follows (fig. 9):

Yes: 50.00% (13)

No: 42.31% (11)

Not sure: 7.69% (2)

There were four comments on question fourteen (14). One (1) commenter said they had never been given information, but found some of their own accord; one (1) commenter from Saskatchewan wrote that they had to source their materials through Princess Margaret Cancer Centre in Ontario; and the final two (2) commenters suggested that ocular melanoma-specific resources are available in cancer centres in both Alberta and Ontario.

Question Fifteen (15): “Do you Wish you had More Support or Information in your Journey with Ocular Melanoma?”

Do you wish you had more support or information in your journey with ocular melanoma?

Answered: 27 Skipped: 0

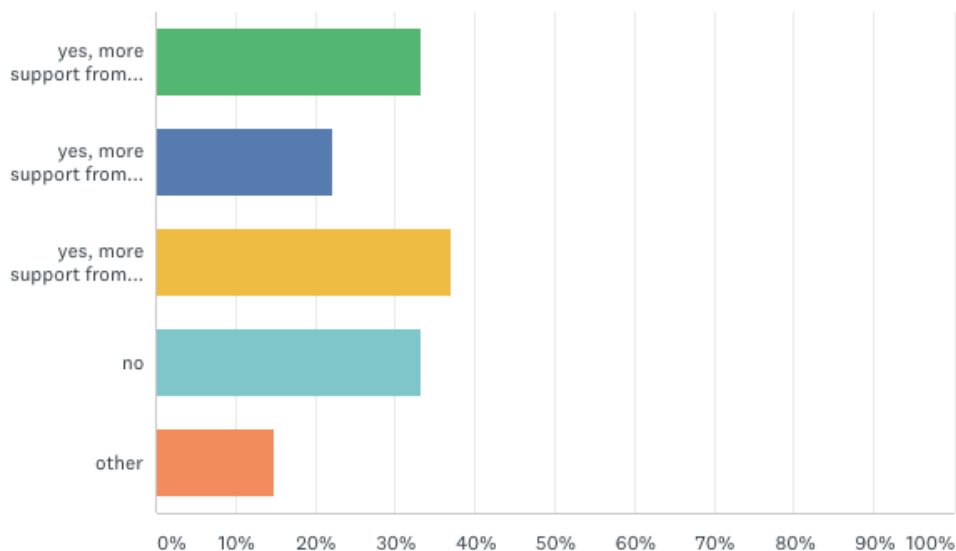


Figure 10: Responses to Question Fifteen (15)

Question fifteen (15) ascertained the amount of satisfaction survey participants felt regarding the amount of support they received during their experience from melanoma. Twenty-seven (27) survey participants answered this question, and it was skipped by zero (0) survey participants. The available answers were “yes, more support from my medical team,” “yes, more support from other patients,” “yes, more support from both my medical team and the chance to connect with other patients,” “no,” and “other.”

The response breakdown was as follows (fig.10, above):

Yes, more support from my medical team: 33.33% (9)

Yes, more support from other patients: 22.22% (6)

Yes, more support from both my medical team and the chance to connect with other patients: 37.04% (10)

No: 33.33% (9)

Other: 14.81% (4)

There were eight (8) comments on question fifteen (15). While two (2) commenters stated that they were satisfied with the amounts of support they had received from their medical team and other patients, five (5) commenters claimed to have experienced a lack of support from their medical team, or had not had the opportunity to meet other patients. Two (2) of these comments, both written by participants from Saskatchewan, noted that they had to pay for their own MRIs, or had no financial support when they had to travel to Ontario because there was no available treatments for ocular melanoma in Saskatchewan.

Question Sixteen (16): “Would you Like to Connect with Other Patients with Ocular Melanoma?”

Question sixteen (16) asked survey participants if they would be interested in meeting more patients that have been diagnosed with ocular melanoma. Twenty-two (22) participants answered this question, and it was skipped by five (5) participants. The available answers were “yes, with primary ocular melanoma patients,” “yes, with metastatic ocular melanoma patients,” and “no.”

The results breakdown was as follows (fig. 11, below):

Yes, with primary ocular melanoma patients: 59.09% (13)

Yes, with metastatic ocular melanoma patients: 50.55% (11)

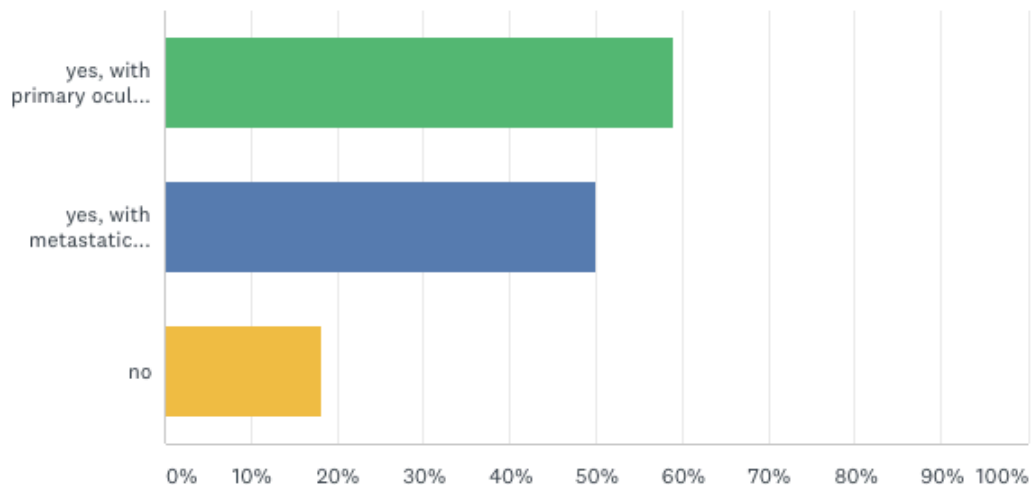
No: 18.18% (4).

There were eight (8) comments associated with question sixteen (16). Of these comments, three (3) suggested that they were open to the possibility of connecting with other ocular melanoma patients, but that they weren’t ready to do so or had not

considered it. Two (2) comments said that they would be interested in supporting other patients and making connections, though they had not done so yet, and two (2) others claimed that they were already in touch with other patients through ocular melanoma facebook pages.

Would you like to connect with other patients with ocular melanoma?

Answered: 22 Skipped: 5



| ANSWER CHOICES | RESPONSES |
|---|-----------|
| yes, with primary ocular melanoma patients | 59.09% 13 |
| yes, with metastatic ocular melanoma patients | 50.00% 11 |
| no | 18.18% 4 |
| Total Respondents: 22 | |

Figure 11: Responses to Question Sixteen (16).

Question Seventeen (17): “Do you have any Links, Online Forums, or Additional Resources that you Currently Use for Information that you would Like to Share, about Ocular Melanoma?”

Question seventeen (17) asks survey participants if they have any resources about ocular melanoma that they would be interested in sharing. This question was

answered by twenty-four (24) survey participants, and skipped by three (3) survey participants. Participants were able to write in their own answers to the question.

Out of the twenty-four (24) responses, eleven (11) participants said they had no resources to share. Facebook groups were shared in the responses, such as: “[Metastatic Ocular Melanoma](#),” “[Ocular Melanoma Support](#),” as were websites such as the [OCU-MEL mailing list](#), [The Ocular Melanoma Foundation](#), the [Eye Cancer Network](#), and the [Cancer Connection message board \(Canadian Cancer Society\)](#).

Question Eighteen (18): Contact Information

In the final question of the survey, participants were given the option to include their email and phone number, in case they were interested in being connected with other ocular melanoma patients. For confidentiality reasons, this information cannot be disclosed in this survey report. If you did not participate in this survey, but are an ocular melanoma patient looking to connect with other ocular melanoma patients, please visit [our website](#) or [email us](#).

Conclusions

The responses to “Understanding Ocular Melanoma in Canada” render it evident that there is an imbalance across Canada regarding the assistance and resources given to patients with ocular melanoma. Nearly 50% of our survey participants reported not being given, or not being sure about the existence of, resources about ocular melanoma at their cancer centre (question 14); therefore, there is a greater need for cancer centres across Canada to be informed about uveal melanoma, to have informational resources on hand for patients, and to be able to connect patients to a network of other patients with ocular melanoma (question 15).

While there was a lack of data from the other prairie provinces, survey participants from Saskatchewan reported that they had to receive their treatments in Ontario, taking on the relocation fee as a personal expense (questions 13, 14). The responses to question twelve (12) suggest that patients in Saskatchewan, Newfoundland, and Alberta have had particular difficulty accessing treatments in their own province, as do some patients in Ontario, as two of our survey participants from Ontario have been referred to clinical trials in Philadelphia (question thirteen (13)). It is evident that ocular melanoma care is overall difficult to access, regardless of your geographical location. The difficulties inherent in treatment access, especially for those in geographically isolated areas, is a frequent issue in Canadian healthcare and it is evident that treatment for ocular melanoma is not an exception. Care for ocular melanoma should be available at all Canadian cancer centres, and if patient relocation is necessary for treatment it should not be at the expense of the patient.

Additionally, responses to question seven (7) indicate that treatment plans for ocular melanoma are exceptionally varied, and that there seems to be space for greater

inclusion of innovative treatments for melanoma, which will ideally increase with improved access markets for these treatments.

Overall, recent developments in precision treatments and increased awareness have improved the ocular melanoma landscape, however there is still much work to be done in standardizing both best care practices and the informational resources available to patients across Canada.

Works Cited

Leyvraz, S. et al. *Precision Medicine for the Treatment of Metastatic Uveal Melanoma; A Pilot Study*. Charite Comprehensive Cancer Center, Charité University Hospital, Berlin, et al. Poster presented at the European Society for Medical Oncology (ESMO) meeting, 2017. Retrieved from: <https://saveyourskin.ca/wp-content/uploads/1218PD-1.pdf>.

Deacon, Nigel and Natalie Richardson. "Save Your Skin Foundation Patient Survey: Understanding Ocular Melanoma in Canada." Save Your Skin Foundation. Survey open from February 2, 2018- July 10, 2018, on the SurveyMonkey platform.