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Introduction

Ocumel Canada, an initiative of Save Your Skin Foundation, ran the survey "The Patient Experience: Treatment of Patients with Ocular Melanoma" in both English and French from April 11, 2022–April 30, 2022. The goals of Ocumel Canada are to increase awareness, advance treatment options, and build a supportive community for those diagnosed with primary and/or metastatic ocular melanoma (OM).[1] This survey contributes to these aims by ascertaining what care ocular melanoma patients are receiving, how these treatments affect their quality of life, and how they are accessing and financing said treatments. This section also reiterated these questions specifically about KIMMTRAK, an immunotherapy treatment currently available for HLA-A*02:01-positive ocular melanoma treatments. The following document reports data from this survey, including figures, and offers some conclusions on the data. Both the English and French surveys are collated together in this report. We thank you for taking the time to read this survey. If you have any questions, please contact Ocumel Canada.

Survey Report

Question 1: What is your gender?

This question ascertained the gender identities of survey participants; 80% of participants identified as "female" and 20% identified as "male."

Question 2: What is your age?

This question gauged the age range of participants. The majority of participants who took the English survey were between "60-69" years of age (28.57%); 25.71% of participants fell in the "30-49" and "50-59" age groups, separately; and 20% of English survey participants were between the ages of "70-79."

Question 3: Which if the following best describes your employment status?

To provide greater context of the lives of survey participants, this question asked about current employment status. Many survey participants were "retired" (42.86%). Other responses selected in descending order include "employed, working full-time" (25.71%), "employed, working part-time" (14.29%), "not able to work because of health-related reasons" (8.57%), "not employed, not looking for work" (5.71%), and "not employed, looking for work" (2.86%).

[1] Ocular melanoma is also known by the name uveal melanoma.

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

Question 4 ascertained the locations of survey participants within Canada. 5.88% of participants reported that they do not live in Canada. Of the Canadian participants, 26.47% live in both "Ontario" and "British Columbia;" 23.53% live in "Alberta;" 8.82% in "Saskatchewan;" and each of the following provinces were selected by 2.94% of participants: "Manitoba," "Newfoundland and Labrador," and "Prince Edward Island," individually.

Question 5: If you do not live in Canada, in what country do you reside?

This question allowed survey participants who responded to question four that they do not live in Canada to write in their places of residence. In what are likely overlaps between questions 4 and 5, two participants wrote that they reside within Canada; the remaining comments indicated that they live in the United States.

Question 6: Were you diagnosed with […]

This question confirmed which form of melanoma survey participants have been diagnosed with. As this survey was created for OM patients, most survey participants have OM, with 80% reporting that they have been diagnosed with "ocular melanoma-primary" and 11.43% with "ocular melanoma-metastatic." 2.86% of participants have been diagnosed with simultaneous "primary and metastatic ocular melanoma," and 5.71% are "not sure" whether their ocular melanoma is primary or metastatic.

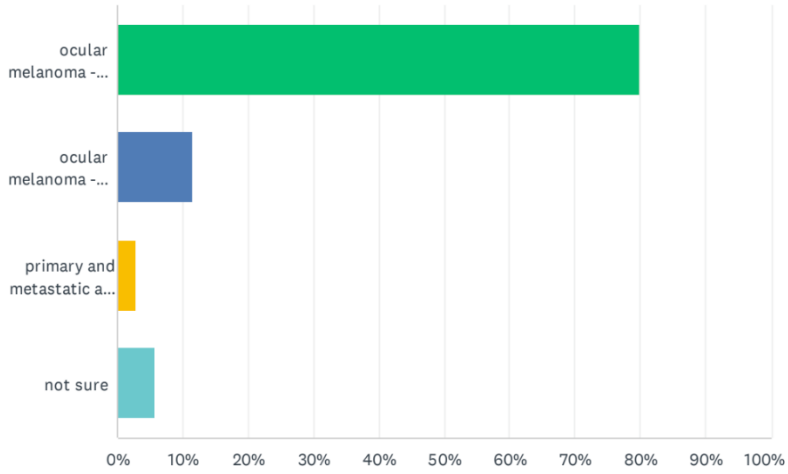

Figure 1: Were you diagnosed with […]

Question 7: In what year were you first diagnosed, whether primary or metastatic?

This question ascertained what year survey participants had been diagnosed with OM in order to map this timeline against the rapidly changing cancer care landscape. Diagnosis years ranged from 1998-2022, with the most frequent diagnosis years in descending order being 2019 (17.14%); 2020 (14.28%); 2016, 2018, and 2022 (11.42% each); 2021 (8.57%), 2010, 2014, and 2017 (5.7% each), and 1998, 2002, 2012, and 2015 (2.85% each).

Question 8: For confirmation of ocular melanoma metastasis, have you had a biopsy?

This question asked survey participants if they have undergone a biopsy to confirm their melanoma diagnosis. The options available to select were "yes, histopathology to confirm melanoma," "yes, for monosomy 3," "yes, for gene expression profiling," "no," and "not sure." The most frequently selected answer was "yes, for gene expression profiling" (33%), followed by "no" (30.30%), "yes, histopathology to confirm melanoma" (21.21%), "yes, for monosomy 3" (12.12%), and "not sure" (9.09%). Keeping in mind the small sample size, these responses still suggest that a significant portion of ocular melanoma do not receive biopsies, and if they do, it is most often for the purpose of gene expression profiling.

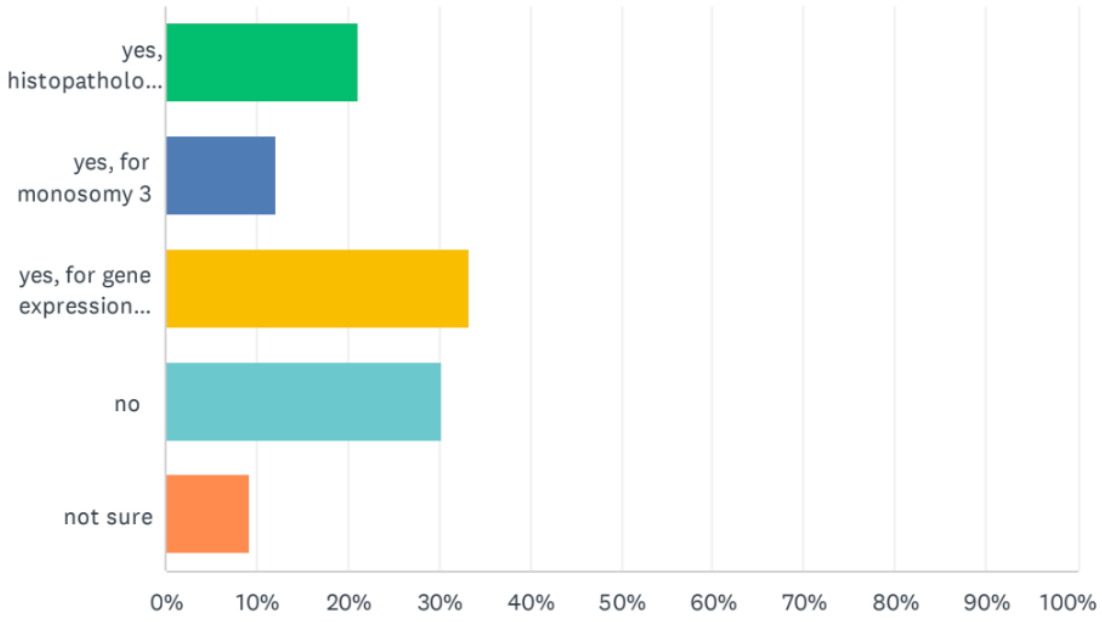

Figure 2: For confirmation of ocular melanoma metastasis, have you had a biopsy?

Question 9: Did you have genetic testing to establish metastatic risk?

This question asked participants whether they have undergone genetic testing to establish their risk level for metastases. Most responses (54.29%) indicate that "yes," they have undergone genetic testing to identify metastasis risks. 34.29% reported that "no," they have not had genetic testing, and 2.86% said they were "not sure." A further 8.57% selected "other" and wrote in specifics about their genetic testing timeline.

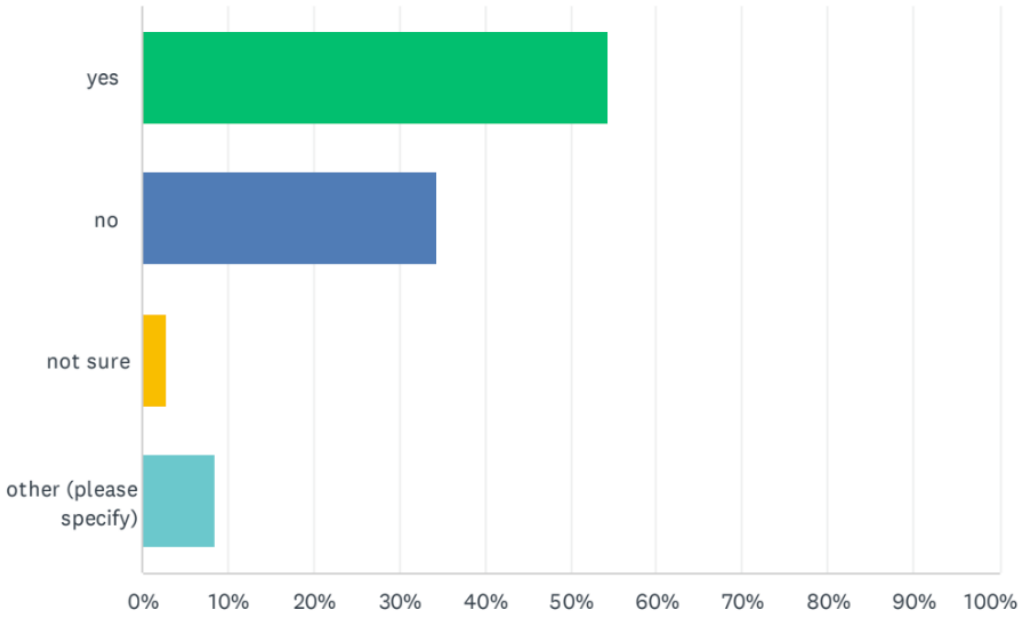

Figure 3: Did you have genetic testing to establish metastatic risk?

Question 10: If you have had genetic testing, did you have to pay for it out-of-pocket?

Question 10 asked whether participants who have had genetic testing had financial support for that portion of their care, or if they had to pay out of pocket. 40% of responses stated that "no," they were not required to cover the costs of their genetic testing, while 20% selected that "yes," they did have to pay for it. 2.86% were "not sure" whether they paid for genetic testing, which is consistent with the responses to question 9 indicating that 2.86% of participants were unsure of whether they have received genetic testing at all. 31.43% selected that the question was "not applicable" to them, likely meaning they have not undergone genetic testing. A further 5.71% selected "other" and wrote in more details, including one participant noting that genetic testing took too long in Canada so they went to the United States for the procedure and another who would have been willing to pay for their own genetic testing but their doctor (which type of doctor was not specified) was unwilling to perform it.

Question 11: If you did not have genetic testing, do you wish you had?

If participants had answered no to the previous question, indicating that they have not received genetic testing, this question asks whether they would have liked to receive it. 54.84% of responses indicated that this question was "not applicable" to them, as they have received genetic testing and 3.23% were "not sure" if they would like to receive genetic testing. 22.58% of participants indicated that "yes," they have not received genetic testing, but would have liked to, while 9.68% selected "no," they have not received genetic testing and do not wish that they had. 9.68% responded with "other" and elaborated on their circumstance in the comments. One of these responses noted that they are currently in the process of receiving genetic testing and another commenter noted that they wanted to receive genetic testing, but they would have had to pay for it out of pocket and their healthcare professional was also not interested in performing the procedure due to the small size of the tumour.

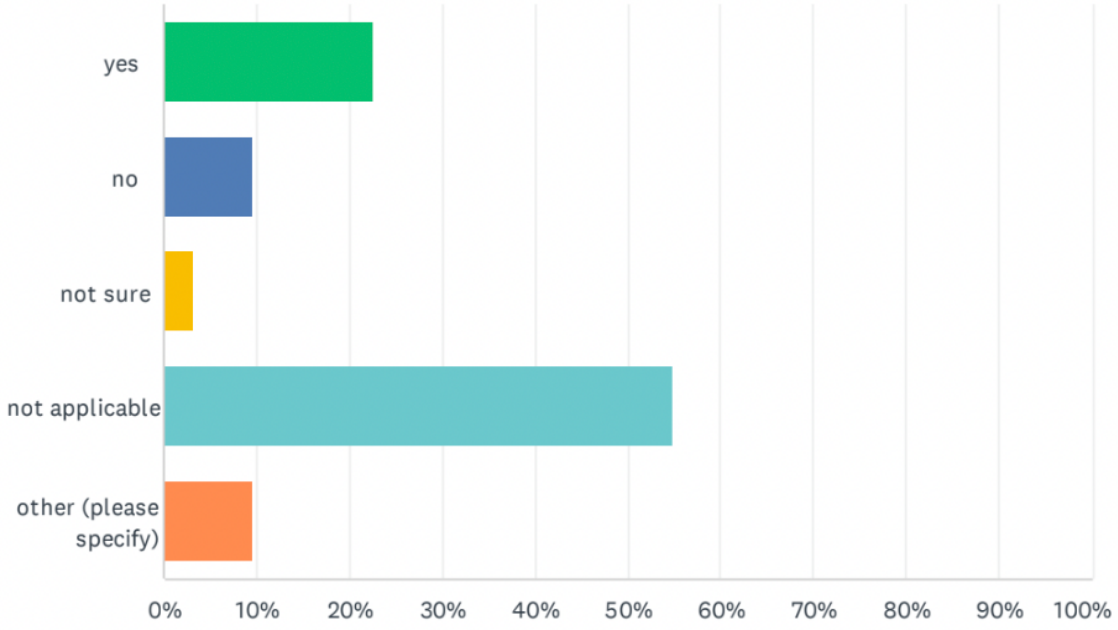

Figure 4: If you did not have genetic testing, do you wish you had?

Question 12: If you have been diagnosed with metastatic OM, did you receive a blood test for (HLA)-A*02:01?

This question determined whether participants with metastatic OM have received blood tests for (HLA)-A*02:01, which is a leukocyte antigen serotype within the HLA-A serotype group that is related to the development of metastases and may influence cell response. 54.29%

of responses reported that this question was "not applicable" to them, likely because they do not have metastatic OM. 22.86% of responses indicated that "yes," they have received blood testing for their metastatic OM; 8.57% reported that "no," they have not received blood testing. 11.43% of responses indicated that they were "not sure" if they have received blood testing for (HLA)-A*02:01 and 2.86% selected "other" and entered comments elaborating on their specific situations.

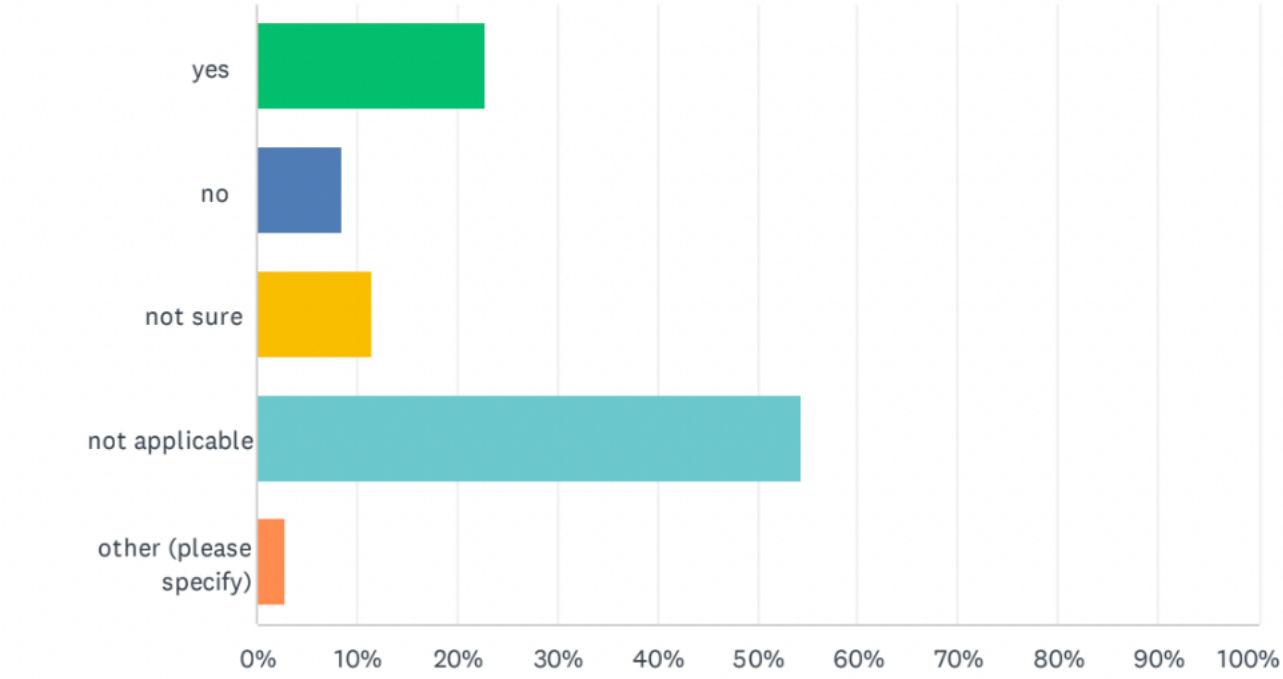

Figure 5: If you have been diagnosed with metastatic OM, did you receive a blood test for (HLA)-A*02:01?

Question 13: If you have been diagnosed with metastatic OM and had (HLA)-A*02:01 testing, are you [(HLA)-A*02:01 positive or (HLA)-A*02:01 negative]?

Question 13 determined whether participants who have been diagnosed with metastatic OM and received blood testing for (HLA)-A*02:01 tested positive or negative, as per question 12. 65.71% of participants, likely a combination of those who were not diagnosed with metastatic OM and those who were, did not receive blood testing. Of those who responded that they did receive blood testing, 25.71% reported that they tested "(HLA)-A*02:01 positive;"

notably, 0% of responses indicated that they had tested "negative." 8.57% of responses said they were "not sure," either of whether they were tested at all or the results of the test.

Question 14: If you did not have (HLA)-A*02:01 blood marker testing, do you wish you had?

This question ascertains whether those with metastatic OM who did not receive blood marker testing for (HLA)-A*02:01 would have wanted to receive that test. 58.82% of participants responded that this question is "not applicable to them," likely because they either did not have metastatic OM, or do have this diagnosis and have received genetic testing. 17.65% of responses indicated that "yes," they wish they have received genetic testing; 5.88% responded that "no," they do not wish they have received genetic testing. 17.65% of participants said they were "not sure," likely a combination of those who are unsure of their diagnosis, whether they received blood marker testing, and/or whether blood marker testing is applicable to them.

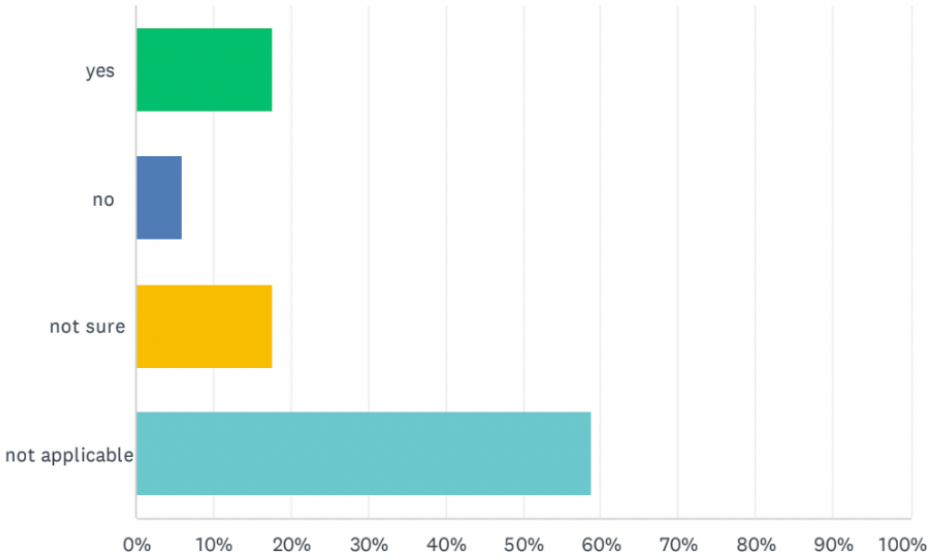

Figure 6: If you did not have (HLA)-A*02:01 blood marker testing, do you wish you had?

Question 15: What has been your experience with this type of cancer? For example, physical, mental, financial, emotional toll etc.

This question asked participants to write about their experience with ocular melanoma. Many responses indicated that their diagnosis has been a detriment to their mental health and caused increased anxiety (60%). Some of these responses linked their anxiety directly to the

rareness of ocular melanoma and corresponding lack of care options or the waiting for responses (11.42%). Several comments also cited loss of vision, including eye loss, as a side effect of either the disease or their treatments (42.85%), and some responses also cited a large financial toll for them (14.28%), especially as some did not have care available to them in their home province and had to travel to receive treatment (17.14%). Other aspects of the experience mentioned included intensity of treatment (2.85%), lack of treatment options (2.85%), pain from primary tumour(s) (2.85%), the shock of diagnosis (2.85%), job loss (2.85%), divorce (2.85%), and fatigue (2.85%).

Question 16: Do you have any ongoing symptoms with this type of cancer? If yes, please list them.

Question 16 asked participants if they are experiencing any ongoing symptoms due to their diagnosis and treatment of OM. While a few responses suggested that they are not experiencing any ongoing symptoms (19.35%), many cited a loss of vision (64.51%). Several also indicated eye pain (16.12%), cataracts (9.67%), flashes of light in the eyes (12.9%), dry eyes (3.22%), macular edema (3.22%), and retinopathy (3.22%). Outside of the eye region, responses cited metastases (6.45%), tumours (6.45%), sub-cutaneous lesions (3.22%), headaches (3.22%), insomnia (3.22%), weight loss (3.22%), temperature intolerance (3.22%), and fatigue (3.22%).

Question 17: Have you ever had treatment for ocular melanoma? Check all that apply.

This question asked participants whether they have ever received treatment for OM. The options available were “brachytherapy,” “proton beam radiation,” “TTT (transpupillary thermotherapy),” “enucleation,” “chemotherapy,” “immunotherapy,” “ablation surgery,” “radiotherapy,” “SBRT (stereotactic body radiation therapy),” “chemoembolization,” “immunoembolization,” “radioembolization,” and “not sure.” If they had received chemotherapy or immunotherapy, participants were asked to specify which treatment they had received.

The majority of responses indicated that they had received “brachytherapy” (91.18%). This was followed by “immunotherapy” (23.25%), “TTT” (8.82%), “enucleation” (5.88%), “radiotherapy” (5.88%), “proton beam radiation” (2.94%), “ablation surgery” (2.94%), and “SBRT” (2.94%). Zero participants indicated that they have received chemotherapy, chemoembolization, immunoembolization, or radioembolization. No responses indicated being “not sure” about treatment received.

Participants who received chemotherapy most often listed tebantafusp, and the most common immunotherapy received was the combination of ipilimumab + nivolumab. Other treatments listed in the comments include surgeries, avastin and anti-VEGF treatment, and cataract surgery.

Question 18: What was your experience with the treatment(s)?

Question 18 asks about survey participants' experiences during their respective treatments. A large portion of these responses indicated that treatment was not as difficult as they expected it to be (28.58%), and a nearly equal number wrote that they experienced substantial side effects (28.52%). A few commenters noted that they received excellent care (14.28%) and that their treatments were successful (11.42%). Some wrote that their treatments were painful, with a couple of these citing brachytherapy as being particularly painful (14.28%). Other responses cited job loss (2.85%), having to travel (2.85%), removal of an eye (2.85%), the stress of waiting between treatments (2.85%), fatigue (2.85%), fear (2.85%), and hope (2.85%) as other effects of the experience.

Question 19: When was your most recent treatment for ocular melanoma?

This question asked participants when they most recently received treatment for ocular melanoma. A large percentage of participants received their most recent treatment around the time of the survey, in either March or April 2022 (37.14%). A few also noted that they have their next treatment at another point in 2022 (11.42%). These figures indicate that most of the survey participants are currently undergoing treatment for OM. 40% indicated that they had received their most recent treatment in 2021 or earlier, with the furthest year indicated being 1998. Some participants specified that their treatments are ongoing (5.71%), or that they are in the follow-up stage (8.57%).

Question 20: Do you receive ongoing surveillance, imaging, follow-ups for primary and/or metastatic OM. If yes, how often?

Here, participants were asked about their current follow-up and/or testing schedule for OM. Most participants have an appointment or receive testing every 3-6 months (82.35%). Depending on how recent their treatments have been, some mentioned receiving follow-up testing weekly (5.88%) or monthly (8.82%), annually (2.94%), or once every two to three years (5.88%). One response mentioned being too early in the process to have an idea of what their follow-up schedule will look like.

Question 21: If you received or are about to receive a treatment for ocular melanoma and your disease was to progress 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.

Question 21 ascertained whether patients would desire additional treatments should their disease progress in the future. Unsurprisingly, most responses indicated that they would be

interested in receiving additional treatments for any recurrence or progression (79.31%). Some responses indicated that they were unsure, either because they are currently early in their cancer journey or because they would want to evaluate their options at the time (13.79%). One response noted that they are currently fighting multiple cancers, and therefore would always be eligible for additional treatments.

Question 22: Are there improvements you would like to see in a new treatment that is not currently achieved in an available treatment?

This question asked participants for their feedback about what they would like to see in future treatments. Several responses said that they were unsure (27.58%); most participants said yes, with some elaboration on what they would ideally like to see in future care options. These responses included longer (6.89%) and increased (13.79%) efficacy, more local availability (3.44%), treatments targeted for people with (HLA)-A*02:01 blood marker positivity (3.44%), and potential for vision restoration (3.44%).

Question 23: How might quality of life for patients, caregivers, and families be different if the new treatment provided those desired improvements? Are there any "trade-offs" that patients/families/caregivers consider when choosing therapy?

This question asked whether the changes in treatments offered by survey participants in the previous question would impact their quality of life. Several answered that they believed it would (70.37%), and some responded that they were unsure what the difference would be (22.22%). Several responses repeated what exact changes in treatment options would improve their quality of life (25.92%); these responses include fewer appointments (3.70%), more options (3.70%), lower costs (14.81%), more local treatment options (11.11%), more assurance that the treatments will be effective (7.40%), and reduction in stress (3.70%). One response also noted that most of these obstacles are worth it for the chance to live.

Question 24: If you were to be offered a treatment on a clinical trial, would you consider taking it?

Question 24 gauged interest in clinical trials. 64.71% of survey participants indicated that "yes," if they were offered enrolment in a clinical trial, they would take it. 0% answered that "no," they would not consider a clinical trial. 35.29% of participants selected that they were "not sure" and elaborated upon their position in the comments. These comments reiterated that the decision would require careful consideration at the time, which would include having more information about the trial, the potential of side effects, expected outcomes, and what kind of results survey participants were seeing with whatever treatment they were on before the trial.

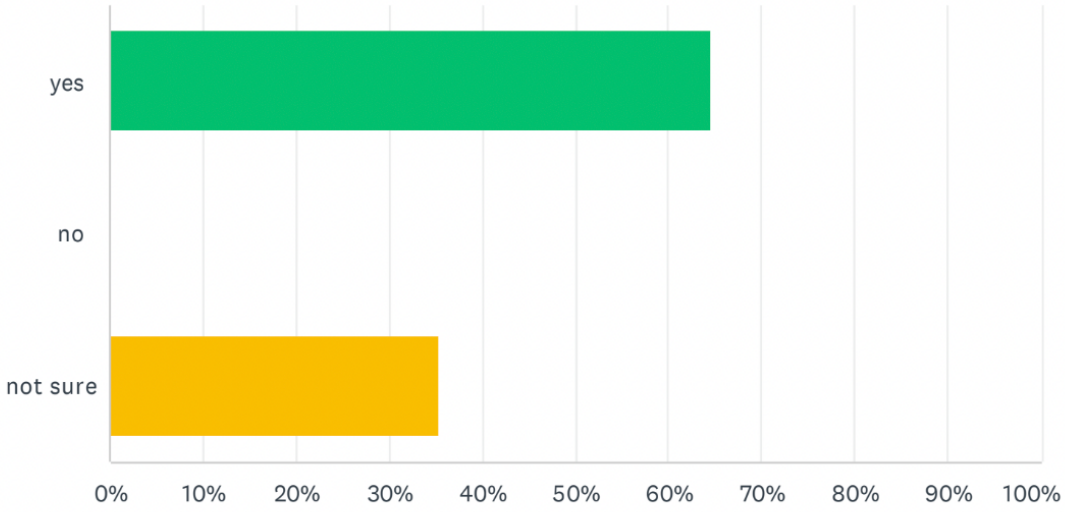

Figure 7: If you were to be offered a treatment on a clinical trial, would you consider taking it?

Question 25: If you received KIMMTRAK ® (tebentafusp-tebn) for unresectable or metastatic ocular melanoma, how did you obtain this treatment?

This question asked survey participants who have received KIMMTRAK® how they accessed and paid for the drug. Options for response included via "clinical trial" (12.50%), "private payer" (0%), "compassionate access" (37.50%), or allowed participants to indicate that they are "not sure" (0%). Participants were also offered the choice to select "other" and elaborate on their responses in the comments (50%). These responses largely indicated that they did not receive KIMMTRAK, though one comment noted that their prescription for KIMMTRAK® is being covered by the Canadian Armed Forces.

Question 26: When did you begin to receive this treatment [KIMMTRAK ®] (month/year)?

This question asked those who have received KIMMTRAK® when they began their treatments. Responses to this question varied, with some responses indicating the question was not applicable to them because they did not receive KIMMTRAK®, or they did not respond to the question for this reason. Specific dates offered ranged from between February 2018 and January 2022.

Question 27: How many courses of treatment did you receive[,] or have you received to date?

This question asked participants how many courses of their respective treatments they have received up until the time the survey was released (April 2022). The range offered by participants who listed numerical values was between 11-25 courses of treatment. One participant outlined that they had received treatment once a week for 3.5 years, followed by treatments approximately every three weeks for maintenance.

Question 28: What (if any) side effects did you experience from this treatment? Select all that apply.

This question established the rate at which certain treatment-related side effects were experienced by participants; they were asked to include every side effect they experienced. Listed in order of frequency, options available to select were "fatigue" (reported by 50% of participants), "skin rash" (50%), "gastrointestinal issues" (25%), "cognitive impairment" (12.50%), "fever" (12.50%), "nausea/vomiting" (0%), "damage to organs" (0%), "breathing problems" (0%), "headaches" (0%), "weight loss or gain" (0%), and "loss or gain of appetite" (0%). 37.50% of participants selected the "other" option and wrote in a response. These responses noted that the question was not applicable to the participant, as they did not receive KIMMTRAK®, or that they are still suffering from certain side effects.

The figure associated with this question is on the following page.

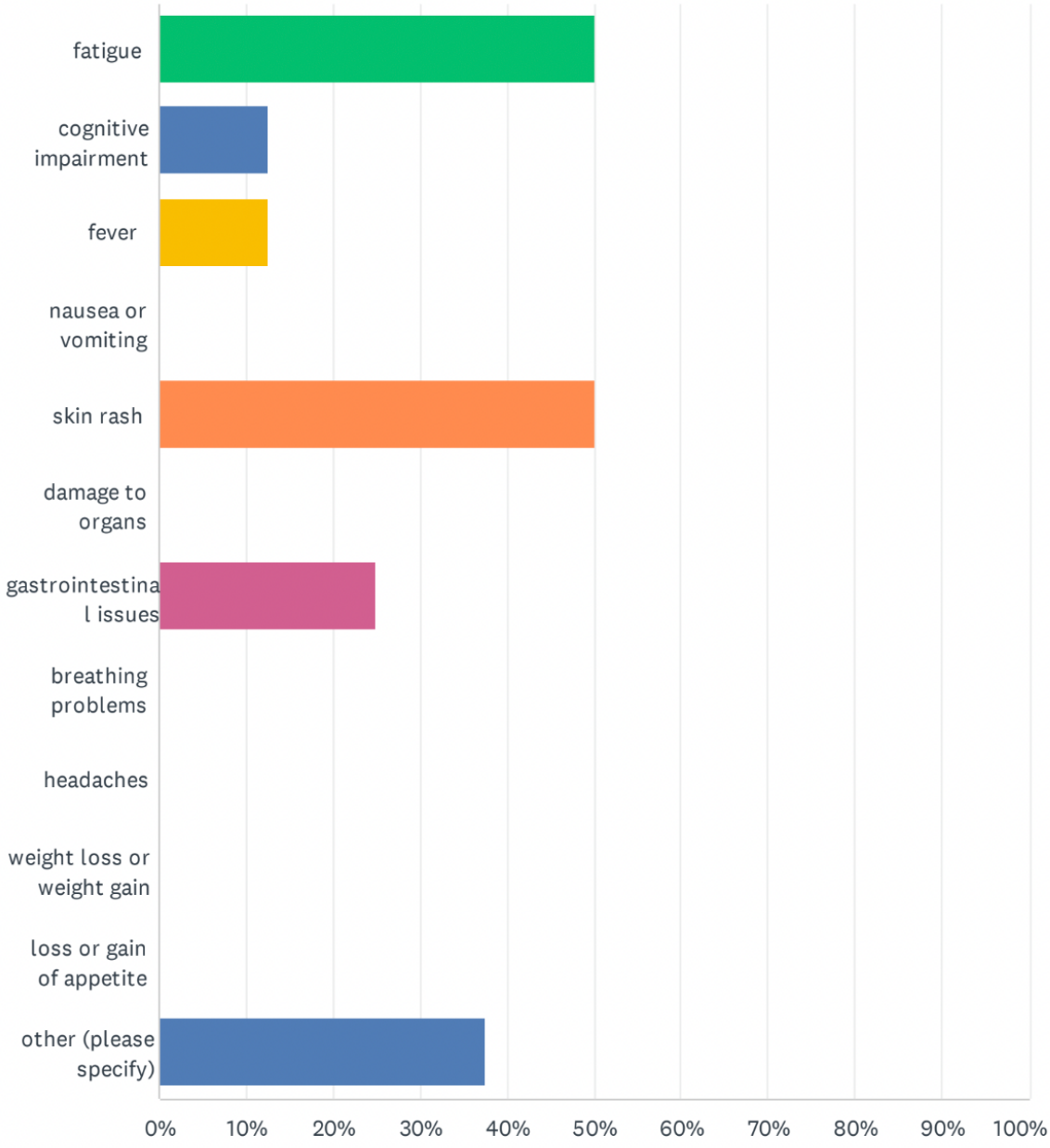

Figure 8: What (if any) side effects did you experience from this treatment? Select all that apply.

Question 29: Were the side effects manageable?

This question asked participants whether they found the side effects they experienced from treatment to be tolerable. This question was scaled, with the available options left to right being "not manageable" (12.50%), "somewhat unmanageable" (0%), "neutral" (0%), "somewhat manageable" (12.50%), "manageable" (50%), and "not applicable" (25%). While no participants specified in the comments, the "not applicable" answers likely represented those who either did not receive KIMMTRAK®, or did not experience side effects.

Question 30: If you experienced side effects from this drug therapy, did the benefits of the treatment outweigh the experience of the side effects?

Question 30 ascertained whether survey participants felt like the side effects of KIMMTRAK® did or did not outweigh the benefits. While 44.44% of participants indicated that the question was "not applicable" to them, likely because they did not receive KIMMTRAK® or experience side effects, the entirety of the remaining 55.56% answered that "yes," the benefits of treatment outweighed the side effects. This response suggests that those receiving cancer treatments are willing to endure most side effects for increased likelihood of survival.

Question 31: Did you experience any hardships that barred you from accessing this drug therapy [KIMMTRAK®]? 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.

This question asked survey participants what kind of hardships they experienced during their treatment. These responses largely involved having to travel to another city, which was both an inconvenience and financial hardship (44.44%). Other responses indicated that slow access timelines were an issue (22.22%), and one response noted that they had to wait for their disease to progress from stage 3A to 4 in order to access care (11.11%). Other responses noted that they did not experience any hardships (33.33%).

Question 32: How important is/was it to you and your family members or caregivers that you received this treatment [KIMMTRAK®]? If you could describe what you as a patient are looking for in new treatments coming to market, what would you say?

Question 32, the final question in the survey, asked what access to treatment means to patients, and what patients are looking for in new treatments coming to market. Overwhelmingly, these responses suggested that treatment access was vitally important to patients and their

family/caregivers (88.88%). Other responses indicated that the question is not applicable to them as they did not receive this treatment (22.22%).

Conclusions

The data from this survey offers us several conclusions regarding the experience of ocular melanoma patients, particularly those who have undergone KIMMTRAK® immunotherapy. When considering these trends, please keep in mind that our sample size is relatively small and that a portion of our survey participants did not receive KIMMTRAK®. In terms of testing, we saw from questions 8, 9, and 13 that these survey participants underwent biopsies most often for the purposes of gene expression profiling (33.33%) and histopathology (21.21%); 54.29% had received genetic testing in order to identify risk of metastasis; and 100% of participants who had received (HLA)-A*02:01 blood marker testing due to a metastatic diagnosis tested positive.

Questions about treatments (17, 18, 20) demonstrated that most survey participants have received brachytherapy (91.18%), that participants were evenly split between treatment being easier than they anticipated (28.58%) and having substantial side effects (28.52%), and 82.35% of survey participants are currently receiving treatment. As per question 16, the most common side effect of OM care is vision loss (64.51%). 64.17% of participants said they would take a clinical trial if offered one (Q24) and 79.31% would want to receive additional treatments in the future if their disease progresses (Q21), indicating a strong determination to survive among survey participants.

The questions surrounding KIMMTRAK® immunotherapy informed us that 75% of participants who have received KIMMTRAK® did so through compassionate access (Q25), the most frequently reported side effects for this treatment are fatigue and skin rash (50% each, question 28). In question 29, 66.6% of participants found these side effects manageable and in question 30, 100% of the participants who had received KIMMTRAK® felt that the benefits of the treatment outweighed the side effects, again demonstrating that survival is worth tolerating the discomfort associated with treatment-related adverse events. 44.44% of these patients, however, did have to experience the inconvenience and financial hardship of travelling to another city for treatment (Q31). KIMMTRAK® is not available as an option for metastatic patients who test negative for HLA A*02-01. This is an issue that creates inequity and needs to be addressed with the utmost urgency, as half the population will test negative.

Thank you for taking the time to read our survey report about the patient experience of ocular, or uveal, melanoma. We hope that you will continue to fight with us for equal and timely access to care for patients with ocular melanoma, melanoma, and non-melanoma skin cancers.

Appendix: Ocular Melanoma Roundtables (October 2022)

Since the online survey data was collected, SYSF has held two virtual and one live roundtables. One virtual roundtable was for patients from Québec, the Atlantic provinces, and Ontario, and the other was for patients in Saskatchewan, Alberta, and British Columbia. There were five patient/caregiver attendees at the eastern virtual roundtable and seven at the western roundtable. Both virtual roundtables took place on October 25th, 2022. The live roundtable was in Victoria, for patients from British Columbia and took place on October 26th, 2022. The live roundtable had eight patient/caregiver attendees.

The demographics from across the roundtables, collected into one data body, were consistent with those from the survey reported above. Of the roundtable attendees, 50% reported having primary disease and 50% have metastatic disease. Every patient at the roundtable had received, or was in the process of receiving, brachytherapy; popular opinion was that the treatment was easier than anticipated in terms of pain and side effects. The most common side effect experienced by roundtable participants was vision loss, which was consistent with the survey. Also consistently with the survey, participants indicated that if their disease progressed from primary to metastatic, and they were offered a clinical trial, they would take it. In terms of testing, 50% had received gene expression profile testing and 100% had received (HLA)-A*02:01 blood marker testing. All metastatic patients are now receiving KIMMTRAK® in their home province, have had the costs covered by compassionate access, and are finding the side effects manageable.