

ocumel canada



AN INITIATIVE OF  
**save your skin**  
FOUNDATION

## **Updating the Ocular Melanoma Care Landscape in Canada**

Survey Report by Ocumel Canada, an initiative of Save Your Skin Foundation  
July 2021

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# INTRODUCTION

In order to continue providing support to the underrepresented population of the Ocular Melanoma (OM) patient, survivor, and caregiver population, Ocumel Canada, an initiative of Save Your Skin Foundation, conducted an online survey to gather patient and caregiver perspectives about the current landscape of OM care across Canada. The primary goals of the survey were to identify priorities for action to improve patient care and support for OM across Canada and to build community support for patients affected by ocular melanoma. The survey was conducted on the SurveyMonkey platform, consisted of 22 questions, and was available in English from April 17th-May 17th, 2021. The survey was advertised through Save Your Skin Foundation social media and partner advocacy organizations. We appreciate the time and opinions of all survey participants.

For access to the full survey results or any other inquiries, contact us at:

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Facebook: <https://www.facebook.com/groups/OcularMelanomaConnect/>

## QUESTION 1: “IN WHICH PROVINCE DO YOU LIVE?”

The first question in the survey determined the provincial demographics of those taking the survey. In descending order, 31.58% of participants were from Ontario; 26.32% from British Columbia; 21.05% from Alberta; 5.26% from Saskatchewan, Prince Edward Island, and Québec individually; 2.63% in Manitoba and Newfoundland and Labrador individually. There were no responses from Nova Scotia, New Brunswick, or any Canadian territory.

## QUESTION 2: “[WHAT TYPE OF OCULAR MELANOMA] WERE YOU DIAGNOSED WITH”

The second question ascertains what type of OM diagnosis the survey participants had received. 84.21% of participants selected “ocular melanoma- primary,” 13.16% “ocular melanoma- metastatic,” and 2.63% were unsure about the details of their diagnosis. This question allowed survey participants to add additional comments if they wished, and six participants added more details about the location or timeline of their diagnosis.

## QUESTION 3: “IN WHAT YEAR WERE YOU FIRST DIAGNOSED, WHETHER PRIMARY OR METASTATIC?”

This question asked what year each survey participant was initially diagnosed with OM, regardless of whether this was a primary or metastatic diagnosis. The earliest diagnosis recorded in the survey was in 2004 (2.94%), followed by 2009 (2.94%), 2010 (11.76%), 2012 (2.94%), 2013 (2.94%), 2014 (8.82%), 2015 (2.94%), 2016 (8.82%), 2017 (14.71%), 2018 (8.82%), 2019 (23.53%), and 2020 (8.82%).

#### QUESTION 4: “FOR CONFIRMATION OF OCULAR MELANOMA METASTASIS, HAVE YOU HAD A BIOPSY?”

This question determined whether participants with a confirmed OM diagnosis have had a biopsy. 38.89% of survey participants responded that they had not had biopsies, whether this was because they had been offered biopsies and declined, had not been offered a biopsy, or they did not have a confirmed OM diagnosis. 30.56% of participants reported having a histopathology to confirm melanoma; 25% had a biopsy for monosomy 3; 19.44% had a biopsy for gene expression profiling; and 2.78% reported being unsure of how to answer the question. This question also allowed participants to select “other” and add more details, an option 22.22% selected. These responses specified the dates of biopsies, whether biopsies were offered to them or not, and/or why they received biopsies.

#### QUESTION 5: “DID YOU HAVE GENETIC TESTING TO ESTABLISH METASTATIC RISK?”

This question ascertained whether survey participants had undergone genetic testing to establish their level of metabolic risk. 55.26% of participants responded that yes, they had; 39.47% responded that they had not; 2.63% were unsure; and 2.63% selected other and filled in more details surrounded the details of their genetic testing experience.

#### QUESTION 6: “IF YOU HAVE HAD GENETIC TESTING, WHICH TEST WAS IT?”

This question followed up the previous question by asking which type of genetic testing survey participants had received, if the question was applicable to them. 38.46% of participants indicated that they had received testing from Impact Genetics; 26.92% received testing from Castle Biosciences; 30.77% were unsure of what type of testing they had received; and 3.85% selected “other” and filled in more details. These responses either elaborated on the type of testing they had received or noted that the question was not applicable to them as they had not received genetic testing.

#### QUESTION 7: “IF YOU HAVE HAD GENETIC TESTING, DID YOU HAVE TO PAY FOR IT OUT-OF-POCKET?”

This question asked the survey participants who had received genetic testing whether they had to pay for it independently. 53.85% of participants reported that they did not pay for their genetic testing and 46.15% did pay for their genetic testing. Participants were given the option to add additional comments to their responses to this question. In this section, participants gave more details about whether their insurance paid for genetic testing and whether they were told that they would have to pay for genetic testing, regardless of whether they received the testing or not. In multiple cases, participants stated that they declined genetic testing because of the cost.

## QUESTION 8: “IF YOU DID NOT HAVE GENETIC TESTING, DO YOU WISH YOU HAD?”

This question determined whether participants who had not received genetic testing would want it. 27.27% of participants stated that yes, they would want genetic testing; 15.15% were unsure; and 6.06% indicated that they would not. 51.52% of participants reported that the question was not applicable to them, as they had received genetic testing. The additional comments on this question saw participants discuss their reasons for wanting genetic testing and their plans for potentially having genetic testing in the future.

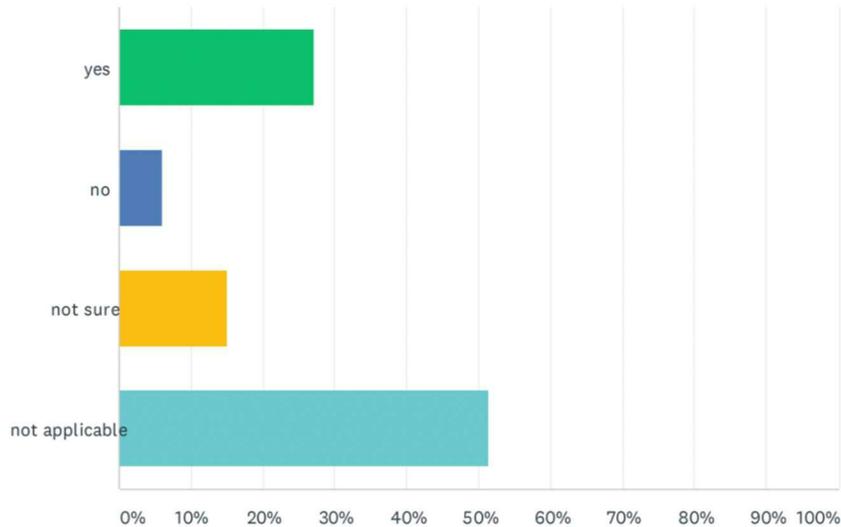


Figure 1: “Q8: If you did not have genetic testing, do you wish you had?”

## QUESTION 9: “HAVE YOU EVER HAD TREATMENT FOR OCULAR MELANOMA? CHECK ALL THAT APPLY”

Question 9 asked participants what kinds of care they had received for their OM, requesting that they include every treatment they have received. In descending order, 78.95% of participants have received brachytherapy; 15.79% enucleation therapy; 7.89% TTT (transpupillary thermotherapy), immunotherapy, and radiotherapy, individually; 2.63% chemotherapy, ablation surgery, and radioembolization, individually. While they were options, zero participants selected the following: proton beam radiation, tebentafusp, sunitinib, chemoembolization, or immunoembolization. 18.42% selected “other” and opted to include more details about their OM care experience; in this section, one participant referenced photo dynamic therapy, an option not included in the survey.

## QUESTION 10: “WHEN WAS YOUR MOST RECENT TREATMENT FOR OCULAR MELANOMA? [BY] MONTH/YEAR”

This question determined when survey participants received their most recent treatment for OM. The most recent treatments reported were within May 2021 (the month this survey was open) by 6.06% of patients; 24.24% of participants reported receiving treatment in the remainder of 2021 (January-April); 21.21% in 2020; 9.09% in 2019; 3.03% in 2018; 12.12% in 2017; and 3.03% in each year between 2015 and 2009. 6.06% of participants stated that they have not yet received treatment for their OM diagnoses.

## QUESTION 11: “DO YOU LIVE IN THE SAME PROVINCE AS WHEN YOU WERE DIAGNOSED WITH OCULAR MELANOMA?”

Question 11 ascertained whether participants are currently living in the same province, and therefore within the same provincial medical system, that they were at the time of their OM diagnosis. The response was overwhelmingly affirmative, with 97.37% of participants confirming that they have remained in the province in which they received a diagnosis. 2.63% answered that they no longer lived in the same province. In the additional comments, multiple survey participants clarified that they reside in the same province but had to travel within that province or to another province to receive treatment.

## QUESTION 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?”

This question determined whether survey participants were able to receive OM treatment in their province of residence. 80.56% responded that yes, they were able to receive treatment in their home province, while 19.44% indicated that they had to travel out of province for treatment.

## QUESTION 13: “HAS YOUR MEDICAL TEAM EVER REFERRED YOU TO AN ONCOLOGIST IN ANOTHER PROVINCE?”

Question 13 asked whether survey participants have ever been referred to an out-of-province oncologist by their medical team. 78.38% of participants stated that they have never been referred to an oncologist outside of their home province, while 21.62% of responders indicated that they have been referred to oncologists outside of their province. This is consistent with the percentage of participants who reported travelling outside of province for OM treatment in question 12, with adjustments for participants who chose to not travel for treatment.

## QUESTION 14: “WHAT IS YOUR PRIORITY IN OM CARE?”

Question 14 asked participants to rank aspects of OM care as “very important,” “important,” “somewhat important,” or “not important.” The aspects of care participants were asked to rank were “treatment for primary disease,” “adjuvant treatment for high-risk patients,” “treatment for metastatic disease,” “scanning and follow-up protocols,” “resources for living with OM diagnosis,” “access to care centre close to home,” and “access to care centre outside of resident province if necessary.”

While every option was ranked “very important” by at least 50% of the survey participants, “treatment for primary disease” had the highest percentage of “very important” responses (94.29%), followed by “treatment for metastatic disease” (91.43%), “scanning and follow-up protocols” (86.49%), and “adjuvant treatment for high-risk patients” (81.82%). While none of these choices were ranked “not important” by a significant margin (no more than 5% for any option), “access to care centre outside of resident province if necessary” was ranked “somewhat important” by 24.24% of survey participants and “access to care centre close to home” was “somewhat important” to 20% of survey participants, suggesting that overall access to care is the highest priority for patients, even if that care requires travelling to another province.

	VERY IMPORTANT	IMPORTANT	SOMEWHAT IMPORTANT	NOT IMPORTANT
treatment for primary disease	94.29% 33	0.00% 0	2.86% 1	2.86% 1
adjuvant treatment for high-risk patients	81.82% 27	12.12% 4	6.06% 2	0.00% 0
treatment for metastatic disease	91.43% 32	5.71% 2	2.86% 1	0.00% 0
scanning and follow-up protocols	86.49% 32	13.51% 5	0.00% 0	0.00% 0
resources for living with OM diagnosis	51.43% 18	31.43% 11	14.29% 5	2.86% 1
access to care centre close to home	57.14% 20	20.00% 7	20.00% 7	2.86% 1
access to care centre outside of resident province if necessary	57.58% 19	15.15% 5	24.24% 8	3.03% 1

Figure 2: “What is your Priority in OM Care?”

## QUESTION 15: “IS THERE ANYTHING YOU FEEL COULD BE IMPROVED IN YOUR OM CARE?”

This question asked survey participants to write in what they feel could be improved in their OM care experience. Fortunately, approximately a quarter of the responses to this question stated that they have no complaints with their OM care at this time. The most consistent issue raised by survey participants is the lack of informational resources for patients regarding OM. Other suggestions included better communication between different parts of a patient’s healthcare team, consistency in doctors and oncologists, more support for patients in coordinating their care plans, funding for care-related travel, allowing for more flexibility in care plans, more options for treatment of metastatic disease, increased access to trial treatments for OM, more structured follow-up routines, and education for oncologists regarding OM.

## QUESTION 16: “DO YOU HAVE A QUESTION OR CONCERN ABOUT YOUR OM CARE THAT YOU NEED HELP ADDRESSING?”

Question 16 asked participants to write in any current questions they might have surrounding their OM diagnosis or treatment. The majority of responses stated that they did not have any specific questions at this time. The questions that survey participants did write included concerns about funding for travel costs, when specific trial drugs will be available in Canada, and the standard of care for their type of OM.

## QUESTION 17: “WITH RESPECT TO YOUR OM CARE AND MEDICAL TEAM, DO YOU FEEL YOU NEED ASSISTANCE WITH ANY OF THE FOLLOWING?”

Here patients were asked to indicate, via ranking, to what extent they feel they need assistance with the following: “medical information and support,” “emotional support,” “OM research updates,” and “travel costs.” Participants were able to rank these issues as “very much,” in that they urgently need assistance, “a lot,” “somewhat,” “not at all,” or “non-applicable.” The most urgent issue for survey participants is “OM research updates,” which was ranked by 38.89% of participants as something they “very much” need assistance with. Overall, 94.44% of survey participants ranked the issue of “OM research updates” as something they required some amount of assistance with (either “very much”/“a lot”/“somewhat”). 50% of participants similarly indicated that they require some level of assistance with travel costs. In turn, 77.79% of survey participants expressed needing assistance with “medical information and support.” “Emotional support” was ranked as the area in which participants needed the least assistance, with 44.12% indicating that they only “somewhat” needed assistance in this area and 35.29% that they did not need assistance whatsoever.

In the comments section for this question, participants added additional concerns, such as inconsistent medical teams, having to pay for travel expenses, access to adjuvant therapies, and missing appointments due to the COVID-19 pandemic.

	VERY MUCH	A LOT	SOMEWHAT	NOT AT ALL	N/A
medical information and support	16.67% 6	30.56% 11	30.56% 11	22.22% 8	0.00% 0
emotional support	8.82% 3	11.76% 4	44.12% 15	35.29% 12	0.00% 0
OM research updates	38.89% 14	22.22% 8	33.33% 12	5.56% 2	0.00% 0
travel costs	23.53% 8	5.88% 2	20.59% 7	41.18% 14	8.82% 3

Figure 3: “With respect to your OM care and medical team, do you feel you need assistance with any of the following?”

## QUESTION 18: “IF YOU COULD CHOOSE, WHICH OF THE FOLLOWING OPTIONS WOULD YOU BE MOST COMFORTABLE WITH? FOR BOTH PRIMARY AND METASTATIC TREATMENT AND MONITORING”

Question 18 asked participants to indicate their preferred option between having “access to specialized care concentrated in a few centres, even if they are not close to [their] city” and “access to centralized care centre as close as possible to where [they] live,” regardless of whether they are receiving treatment for primary or metastatic OM. The majority of participants, 56.76%, chose “access to centralized care centre as close as possible to where [they] live” and 43.24% chose “access to specialized care concentrated in a few centres, even if they are not close to [their] city.”

This question allowed participants to provide additional details in the comments section. Several of these comments pointed to the fact that there is a lack of specialized care centres for OM in Canada outside of Toronto. Multiple comments also suggested that, for reasons including age and financial hardship, travelling to another city for treatment would not be feasible.

## QUESTION 19: “DO YOU FEEL THAT PROVINCIAL MEDICAL PLANS SHOULD COVER ESSENTIAL TRAVEL FOR OM PATIENTS?”

In question 19, participants were asked whether they think provincial medical plans should cover travel costs for OM patients. 91.89% of participants answered that they believe provincial medical plans should assist patients who need to travel to receive specialized treatment. 8.11% of participants replied that they do not believe that travel costs should be covered by provincial media plans. In the comments section, the majority of replies elaborated on why they believe provincial medical plans should assist with travel costs and how helpful it would be for them if these costs were covered. One comment did suggest, however, that assistance with travel costs for cancer treatments generally should be covered and that this question is bigger than just OM.

## QUESTION 20: “IF POSSIBLE, PLEASE SHARE 1-2 THINGS THAT WERE THE MOST CHALLENGING ABOUT YOUR DIAGNOSIS/TREATMENT/OM CARE EXPERIENCE.”

This question asked survey participants to offer one or two aspects of their experience with OM that were especially challenging. In descending order of frequency, participants mentioned loss of vision in the afflicted eye; lack of compassion or professionalism, which largely seemed to stem from a lack of awareness about OM, in their healthcare team; the lack of information available about OM; the lack of financial support; fatigue because of care experience; the lack of metastatic OM treatment in Canada and the need to travel for care; surprise about their diagnosis, as they had never heard of OM; a lack of emotional support; side effects; the massive change in their lives; and the mental wellness hardships they were facing.

## QUESTION 21: “IS THERE ANYTHING ELSE YOU WISH TO COMMUNICATE REGARDING YOUR OM CARE AT THIS TIME?”

Question 21 asked participants whether they have anything else that they wish to communicate about their OM care experience. Aspects of their experience that participants raised include side effect of treatments; the disorganization of the medical system; anxiety about test results; access to treatments; travel costs; the desire for more information about incoming treatments; a lack of follow up; the need for more information; and a need for support groups.

## QUESTION 22: “WITH RESPECT TO YOUR OM CARE EXPERIENCE SINCE THE BEGINNING OF THE COVID-19 PANDEMIC, PLEASE CONSIDER THE FOLLOWING [...]”

This question was specifically about the effect of the COVID-19 pandemic on participants’ care experience. This question asked participants to rate aspects of COVID-19-related circumstances in terms of whether “yes [they have been affected],” “no [they have not been affected],” “no opinion,” or “not applicable,” and they also had the option to write additional comments if they wished. The questions participants were asked to rank included “has your treatment been affected,” “have your scanning or follow-ups been affected,” “has your disease worsened during the pandemic,” “has the pandemic increased your general stress levels,” “has the pandemic increased your stress around OM,” “have you been vaccinated,” and “will you choose to be vaccinated.”

Of these questions, participants most frequently answered “yes [they have been affected]” to questions about the COVID-19 vaccine, with 73.53% of participants stating that they will be vaccinated when given the opportunity and 70.27% responded that they have been vaccinated.<sup>1</sup> As only 2.94% of participants indicated that they will not get the shot, this indicates that the vast majority of survey participants have, or will be getting, the vaccine. In terms of stress levels, 62.16% of participants stated that the pandemic has increased their general stress levels and only 29.73% said that the pandemic has increased their OM-related stress. The lower percentage of participants being stressed about their OM in particular is likely related to the rates of care interruptions due to COVID-19, which, while not low, are surprising given the strain put on the medical care system by COVID-19. 67.57% of participants reported that their treatment has not been affected by the pandemic and 56.76% that their scanning or follow-ups have not been affected. Therefore, there have been more interruptions in terms of scans and follow-ups than treatment. Fortunately, the majority of responses (81.08%) have had no disease progression during the pandemic.

In the comments section for this question, participants raised a variety of issues surrounding their experience having OM during the COVID-19 pandemic. Participants noted having treatments and follow-ups delayed, the inability to see their oncologist, issues surrounding travel in terms of delayed flight and anxiety about travelling during the pandemic, concerns about having a COVID vaccine while receiving treatment, social isolation, and suggesting that cancer patients should have priority in terms of getting their first or second vaccine dose.

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<sup>1</sup> As this survey ran through April and May, 2021, not all participants had been given the opportunity to be vaccinated at the time of the survey.

## CONCLUSION: THE OCULAR MELANOMA LANDSCAPE IN CANADA, 2021

The results of the “Ocumel Canada Patient Survey” demonstrate that the demographics of the survey consisted of a majority of primary ocular melanoma patients (84.21%, question 2), largely spread out between Ontario (31.58%, question 1), British Columbia (26.32%), and Alberta (21.05%). The participants were diagnosed with OM in a range of years from 2009-2020.

In terms of testing, 44.44% of participants have received biopsies for either monosomy 3 or gene expression profiling (question 4) and 55.26% have had genetic testing to discern metastatic risk (question 5). The majority of these genetic tests were created by Impact Genetics (38.46%, question 6) or Castle Biosciences (26.92%). In terms of payment for genetic testing, the results were split nearly down the middle between participants who did not pay for their testing out of pocket (53.85%, question 7) and those who did (46.15%).

When asked about their priorities for OM care (question 14), the options ranked as “very important” by survey participants were “treatment for primary disease” (94.29%), “treatment for metastatic disease” (91.43%), “scanning and follow-up protocols” (86.49%), and adjuvant treatment for high-risk patients” (81.82%). When asked what could be improved about their OM experience (question 15), the most frequently cited issues by survey participants were a lack of informational resources regarding OM, communication and consistency issues with different parts of their healthcare team, and the need for increased access to trial treatments. In terms of issues with OM care that survey participants desire assistance with (question 17), “OM research interests” was the most frequently cited (94.44%) followed by assistance with travel costs (50%).

Question 9 (“have you ever had treatment for ocular melanoma?”) demonstrated that while survey participants have undergone a variety of treatments, the majority have received brachytherapy (78.95%). The highest concentration of participants (30.3%, question 10) have received treatment within 2021. 80.56% of participants were able to receive treatment in their home province, while the remainder had to travel for treatment (question 12). While the slight majority would prefer to have “access to a centralized care centre as close as possible to where [they] live” (56.76%, question 18), 43.24% said they would prefer access to a specialized care centre, even if they have to travel for treatment. This makes it clear that the demand for specialized OM treatment is strong enough that patients would be willing to travel for it if need be. However, in question 19 (“do you feel that provincial medical plans should cover essential travel for OM patients?”) 91.89% of participants suggested that they believe provincial medical plans should assist with these travel costs and in questions 20 and 21 (“share 1-2 things that were the most challenging about your diagnosis/treatment/OM care experience” and “is there anything else you wish to communicate regarding your OM care at this time?”) travel costs were consistently mentioned as a difficulty that participants faced in their OM care. Therefore, while patients are willing to travel, it poses a significant financial hardship that is not always mitigated by provincial health insurance.

This is a time of unprecedented hope for metastatic OM patients in Canada as we are beginning to see access to treatments. This is the change in tide that we have been waiting for for a very long time.

Canada’s universal healthcare system, though province and territory based, should make better communication and coordination possible and it is certainly desirable from the patient perspective. Empowering patients to advocate for themselves: better follow up, appropriate treatments, routine biopsies where possible, access to clinical trials, social/emotional support and financial support would help patients deal with their challenging diagnosis. Ocumel Canada continues to monitor and support work being done in this field, and continues to advocate for OM patients to have access to appropriate and timely care and treatment options.

### **About Ocumel Canada**

Ocumel Canada, an initiative of Save Your Skin Foundation, was formed to increase awareness, advance treatment options, and build a supportive community for those diagnosed with primary and/or metastatic OM. Ocumel Canada is in close collaboration with a global Medical Advisory Board and partner patient representation organizations with the intention to build on international best practices to improve patient outcomes for Canadians touched by this disease. Save Your Skin Foundation (SYSF) is a national patient-led not-for-profit group dedicated to the fight against non-melanoma skin cancers, melanoma and ocular melanoma through nationwide education, advocacy, and awareness initiatives. Save Your Skin Foundation is committed to playing an active role in reducing the incidence of skin cancer in Canada, and to providing compassionate support for all Canadians living with skin cancers.

To learn more please view these links:

[www.ocumelcanada.ca](http://www.ocumelcanada.ca)

[www.facebook.com/groups/OcularMelanomaConnect/](https://www.facebook.com/groups/OcularMelanomaConnect/)