Patient Survey: Treatment Plan Decision-Making

Save Your Skin Foundation (SYSF)
A survey developed collaboratively with Bristol Myers Squibb (BMS)

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Introduction

The survey "Patient Survey: Treatment Plan Decision-Making" was a collaboration between Save Your Skin Foundation (SYSF), a Canadian melanoma, non-melanoma skin cancer (NMSC), and ocular melanoma patient group, and the global biopharmaceutical Bristol Myers Squibb (BMS). The survey was released in both English and French by SYSF. The English language version was disseminated from September 10 to October 10, 2022 and accrued 64 responses at the time of data collection; the French language version was open from September 10 to October 24 and received 11 responses. The report below includes figures from the original report, discussions of the data, and offers some conclusions we may draw from these responses. The data presented in the main body of this report is based on the English language survey and a brief report on the French language survey will appear towards the end of the report. Thank you to those who responded to the survey and to BMS for collaborating with us on this project.

English Language Survey Data

Question 1: What is your gender identification?

The responses to question one determined that 18.75% of survey participants identify as "male," while 81.25% identify as "female."

ANSWER CHOICES	RESPONSES	
Male	18.75%	12
Female	81.25%	52
Non-binary	0.00%	0
Would rather not say	0.00%	0
Other (please specify)	0.00%	0
TOTAL		64

Figure 1: What is your gender identification?

Question 2: What is your age?

Question two confirmed the age of survey participants. 3.13% of responses indicated that participants are between "18-29" years of age; 12.50% between "30-49;" 23.44% between "50-59;" 42.19% between "60-69;" 14.06% between "70-79;" and 4.69% between "80-89." These results demonstrate that most survey participants (65.63%) are between the ages of 50-69.

ANSWER CHOICES	RESPONSES	
18-29	3.13%	2
30-49	12.50%	8
50-59	23.44%	15
60-69	42.19%	27
70-79	14.06%	9
80-89	4.69%	3
90 or older	0.00%	0
TOTAL		64

Figure 2: What is your age?

Question 3: In which province are you located? If not from Canada, please specify.

This question determined the geography of survey participants across Canada. The largest groups of participants reside in "British Columbia" (36.51%) and "Ontario" (25.40%). Otherwise, 17.46% of participants live in "Alberta;" 6.35% in "Saskatchewan;" 3.17% in "Manitoba;" 3.17% in "Nova Scotia;" and 3.17% in "Prince Edward Island." There were zero participants from "Québec," "New Brunswick," "Newfoundland & Labrador," or any of the three Canadian Territories. 4.76% of participants responded that they do not live in Canada but did not offer any further information.

ANSWER CHOICES	RESPONSES	
British Columbia	36.51%	23
Alberta	17.46%	11
Saskatchewan	6.35%	4
Manitoba	3.17%	2
Ontario	25.40%	16
Quebec	0.00%	0
New Brunswick	0.00%	0
Nova Scotia	3.17%	2
Newfoundland & Labrador	0.00%	0
Prince Edward Island	3.17%	2
Yukon, Northwest Territories or Nunavut	0.00%	0
I do not live in Canada	4.76%	3
TOTAL		63

Figure 3: In which province are you located?

Question 4: What were you diagnosed with?

This question determined which cancer type survey participants had been diagnosed with between "melanoma," "non-melanoma skin cancer (NMSC)," and "ocular melanoma." Most responses (68.75%) indicated that they had been diagnosed with "melanoma," 7.81% with "NMSC," and 17.19% with "ocular melanoma." Four participants offered more detail, with two of these indicating that they have basal cell carcinoma (NMSC), one has mucosal melanoma, and one has nodular melanoma.

ANSWER CHOICES	RESPONSES	
Melanoma	68.75%	44
Non-melanoma skin cancer	7.81%	5
Ocular melanoma	17.19%	11
Other (please specify)	6.25%	4
TOTAL		64

Figure 4: What were you diagnosed with?

Question 5: In what year were you first diagnosed?

Question 5 ascertained the diagnosis year of each survey participant. There were 63 responses to this question. The period from 2019-2022 saw the most diagnoses (2022: eight responses or 12.7%; 2021: seven responses or 11.11%; 2020: five responses or 7.94%; 2019: 13 responses or 20.63%), implying either an increase in the frequency of melanoma, ocular melanoma, or NMSC diagnoses, that patients are increasingly likely to connect with patient organizations, or that patients are more likely to be involved with patient organizations in the years immediately following their diagnosis. Moving backwards chronologically, one survey participant was diagnosed in 2018 (1.59%), three in 2017 (4.76%), four in 2016 (6.35%), two in 2015 (3.17%), three in 2014 (4.76%), three in 2013 (4.76%), one in 2009 (1.59%), two in 2005 (3.17%), one in 1998 (1.59%), one in 1996 (1.59%), one in 1989 (1.59%), and one in 1984 (1.59%).

Question 6: What was the approximate duration of your visit at the time of diagnosis?

Here, patients were asked about the approximate duration of their visit at the time of their diagnosis. 33.33% responded that this visit lasted "less than 15 minutes," 20.63% selected "15-30 minutes," 15.87% "30-45 minutes," 4.76% "45-60 minutes," and 20.63% "an hour or more." 4.76% selected that they did not remember how long this appointment was. While this survey does not ask participants whether they felt this appointment length was adequate, it would be interesting to see whether patients felt that a 15-minute visit was sufficient to have this news explained to them.

ANSWER CHOICES	RESPONSES	
Less than 15 minutes	33.33%	21
15-30 minutes	20.63%	13
30-45 minutes	15.87%	10
45-60 minutes	4.76%	3
1 hour or more	20.63%	13
Unsure/don't recall	4.76%	3
TOTAL		63

Figure 5: What was the approximate duration of your visit at the time of diagnosis?

Question 7: Please rank the following factors in order of importance to discuss with your healthcare team at the time of your diagnosis, with 1 being the most important.

Question seven asked patients to order the following considerations based on their priority at the time of diagnosis: "care plan," "prognosis," "treatment timeline," "quality of life," and "financial considerations." Total scores were generated based on the frequency with which each answer was selected at each priority level. Based on the survey score, the most important consideration to survey participants at the time of diagnosis was "prognosis," with a score of 4.13. This was followed by "treatment timeline" (3.73), "care plan" (3.68), "quality of life" (2.41), and "financial considerations" (1.37). Perhaps unsurprisingly, this data clearly demonstrates that patients are more invested in survival than anything else.

	1	2	3	4	5	TOTAL	SCORE
Care plan	30.51% 18	23.73% 14	30.51% 18	13.56% 8	1.69% 1	59	3.68
Prognosis	49.18% 30	24.59% 15	16.39% 10	9.84% 6	0.00% 0	61	4.13
Treatment timeline	15.00% 9	50.00% 30	28.33% 17	6.67% 4	0.00% 0	60	3.73
Quality of life	5.08% 3	6.78% 4	20.34% 12	59.32% 35	8.47% 5	59	2.41
Financial considerations	6.67% 4	0.00% 0	1.67% 1	6.67% 4	85.00% 51	60	1.37

Figure 6: Please rank the following factors in order of importance to discuss with your healthcare team at the time of your diagnosis, with 1 being the most important.

Question 8: Were the topics referenced in the previous question (care plan, prognosis, treatment timeline, quality of life, financial considerations) discussed at the time of your diagnosis?

Question eight elaborated on question seven, asking participants if the previously mentioned topics (care plan, prognosis, treatment timeline, quality of life, financial considerations) were indeed discussed with their healthcare team at the time of diagnosis. 59.38% of responses indicated that these concerns were "somewhat" discussed by their healthcare team, indicating that some of these topics were not brought up at the diagnosis appointment. 20.31% of responses answered that "yes," these topics were discussed, and 15.63% responded that "no," they were not. 3.13% indicated that they "don't recall" whether these considerations were discussed during their initial appointment. 1.56% of participants selected "other" and added a comment, which elaborated on their diagnosis timeline.

ANSWER CHOICES	RESPONSES	
Yes	20.31%	13
Somewhat	59.38%	38
No	15.63%	10
Don't recall	3.13%	2
Other (please specify)	1.56%	1
TOTAL		64

Figure 7: Were the topics referenced in the previous question (care plan, prognosis, treatment timeline, quality of life, financial considerations) discussed at the time of your diagnosis?

Question 9: How many visits did you have before making a treatment decision?

This question asked participants how many appointments they had with their healthcare team between diagnosis and determining an initial treatment plan. 51.56% of participants responded that a treatment plan was determined "at [the] time of diagnosis;" 39.06% "between the first and third visits;" 1.56% "between the fourth and fifth visits;" and 3.13% at the "fifth visit or later." 4.69% selected "other," and included comments outlining their treatment decision-making timeline.

ANSWER CHOICES	RESPONSES	
At time of diagnosis	51.56%	33
Between the first and third visits	39.06%	25
Between the fourth and fifth visits	1.56%	1
Fifth visit or later	3.13%	2
Other (please specify)	4.69%	3
TOTAL		64

Figure 8: How many visits did you have before making a treatment decision?

Question 10: What would have been the ideal length of time for you to make your treatment decision?

Question ten responded to question nine, asking participants what their ideal timeline is between diagnosis and developing a treatment plan. The percentage of participants that responded "at time of diagnosis" matched the percentage of responses indicating that they had been offered a treatment plan at the time of diagnosis in the previous question (51.56%), suggesting that patients both desire, and generally receive, a treatment plan immediately. 45.31% indicated that they received a treatment plan "between the first and third visits," 1.56% "between

the fourth and fifth visits," and 1.56% at the "fifth visit or later." This data demonstrates that the healthcare teams responsible for this group developed treatment plans along the timeline desired by patients.

ANSWER CHOICES	RESPONSES	
At time of diagnosis	51.56%	33
Between the first and third visits	45.31%	29
Between the fourth and fifth visits	1.56%	1
Fifth visit or later	1.56%	1
Other (please specify)	0.00%	0
TOTAL		64

Figure 9: What would have been the ideal length of time for you to make your treatment decision?

Question 11: From whom did you receive your cancer-related information and/or education?

This question asked survey participants to select all the members of their healthcare team who provided them with cancer-related information. The options were "medical oncologist," "oncology nurse," a team of nurses ("multiple different nurses"), "nurse navigator," "family members," and "other," which allowed responders to fill in comments. 62.50% of participants selected "medical oncologist;" 18.75% "oncology nurse;" 4.69% "multiple different nurses;" 6.25% "nurse navigator;" and 6.25% "family members." 48.44% selected "other" and specified other sources of information. Among these were listed ocular oncologists (two mentions), plastic surgeons (two mentions), patient groups (three mentions of SYSF), dermatologists (seven mentions), online resources (five mentions), and surgeons or surgical oncologists (three mentions).

ANSWER CHOICES	RESPONSES	
Medical oncologist	62.50%	40
Oncology nurse	18.75%	12
Multiple different nurses	4.69%	3
Nurse navigator	6.25%	4
Family members	6.25%	4
Other (please specify)	48.44%	31
Total Respondents: 64		

Figure 10: From whom did you receive your cancer-related information and/or education?

Question 12: Of the cancer treatment-related information you received, was it easy for you to understand?

Question 12 asked participants whether they found the cancer-related information they were offered by their healthcare team to be digestible. They were asked to rank their understanding of this information on a five-point scale ranging from "I understood none of the information" to "I understood all of the information." Fortunately, the majority of participants indicated that they either "understood all of the information" (32.81%) or "understood most, but not all, of the information" (43.75%). 14.06% responded that they "understood about half of the information" and 9.38% that they "understood a little bit of the information." 0% of participants indicated that they "understood none of the information."

	I UNDERSTOOD NONE OF THE INFORMATION	I UNDERSTOOD A LITTLE BIT OF THE INFORMATION	I UNDERSTOOD ABOUT HALF OF THE INFORMATION	I UNDERSTOOD MOST, BUT NOT ALL, OF THE INFORMATION	I UNDERSTOOD ALL OF THE INFORMATION	TOTAL	WEIGHTED AVERAGE
☆	0.00%	9.38%	14.06%	43.75%	32.81%		
	0	6	9	28	21	64	4.00

Figure 11: Of the cancer treatment-related information you received, was it easy for you to understand?

Question 13: In addition to your healthcare team, where else did you locate information about your treatments? Please list these below.

Here, survey participants listed resources other than their healthcare team from which they had received cancer-related information. 63 participants responded to this question and several mentioned more than one source of information in their response. The most frequently cited source of information was the internet (52 mentions; 82.54%), including nine references to patient groups (14.29%). Medical literature of various kinds (articles, pamphlets) were cited nine times (14.29%). 12 participants mentioned receiving information from friends or family (19.05%) and five from their general practitioner (7.94%).

Question 14: How consistent were the members of your healthcare team? Did they change between your diagnosis and starting treatment? (select all that apply)

Question 14 asked about the consistency of participants' healthcare teams after their diagnosis. The majority of responses (68.75%) indicated that there were "no changes" in their healthcare team between diagnosis and treatment. 10.94% mentioned that their "medical oncologist(s) changed," 4.69% that their "nurse/nursing team" changed, and 9.38% that they "changed clinics or hospitals." 18.75% selected "other" and added comments which specified the changes they saw in their healthcare team in this period.

ANSWER CHOICES	RESPONSES	
No changes	68.75%	44
Medical oncologist(s) changed	10.94%	7
Nurse/nursing team changed	4.69%	3
Changed clinics/hospitals	9.38%	6
Other (please specify)	18.75%	12
Total Respondents: 64		

Figure 12: How consistent were the members of your healthcare team? Did they change between your diagnosis and starting treatment? (select all that apply)

Question 15: How much involvement did you have in your treatment selection?

At this point in the survey, participants were asked about their level of involvement in developing their treatment plan. They were asked to rank their involvement on a scale from "not involved at all" to "made the decision entirely independently." Most participants fell in the middle of this scale, with 51.56% noting that they felt "appropriately involved" and 21.88% that they "[received] some guidance, but largely made the decision independently." A further 7.81% felt that they "made the decision entirely independently." On the other end of the scale, 7.81% expressed having "a bit of involvement, but would have liked more" and 10.94% were "not involved at all." Overall, the results from this question demonstrate that patients feel like they are reasonably involved with their treatment decision-making.

	NOT INVOLVED AT ALL	A BIT OF INVOLVEMENT, BUT WOULD HAVE LIKED MORE	APPROPRIATELY INVOLVED	SOME GUIDANCE, BUT LARGELY MADE THE DECISION INDEPENDENTLY	MADE THE DECISION ENTIRELY INDEPENDENTLY	TOTAL	WEIGHTED AVERAGE
☆	10.94% 7	7.81% 5	51.56% 33	21.88% 14	7.81% 5	64	3.08

Figure 13: How much involvement did you have in your treatment selection?

Question 16: On this scale, was your level of involvement in treatment decision-making optimal for you? Would you desire greater or less involvement?

Question 16 followed up on the previous question by asking participants whether their level of involvement in treatment decision-making was ideal for them. They were asked to mark their satisfaction with their level of involvement on a scale from "I would have liked to have had much more input" to "too much of the decision was left to me." These responses were largely positive, with 73.44% of participants stating that they "had an appropriate level of input" in their treatment-making decisions. In terms of those who would have liked more guidance, 12.50% indicated that they "would have liked more guidance when making this decision" and 1.56% that "too much of the decision was left to [them]." On the opposite end of the scale, 7.81% "would like to have had a little more input" and 4.69% "would have liked to have had much more input."

	I WOULD HAVE LIKED TO HAVE HAD MUCH MORE INPUT	I WOULD LIKE TO HAVE HAD A LITTLE MORE INPUT	I HAD AN APPROPRIATE LEVEL OF INPUT	I WOULD HAVE LIKED MORE GUIDANCE WHEN MAKING THIS DECISION	TOO MUCH OF THE DECISION WAS LEFT TO ME	TOTAL	WEIGHTED AVERAGE
☆	4.69% 3	7.81% 5	73.44% 47	12.50% 8	1.56% 1	64	2.98

Figure 14: On this scale, was your level of involvement in treatment decision-making optimal for you? Would you desire greater or less involvement?

Question 17: Please rank the following factors by level of importance to you when creating a treatment plan, with 1 being the most important.

Here, patients were asked to rank several factors from 1-5 in order of priority when creating a treatment plan. The considerations listed were "dosing schedule/logistics," "long-term survival," "risk of adverse events/side effects," "financial concerns," and "lifestyle and family implications." As in previous questions, scores were generated based on the frequency with which each answer was selected at each priority level. In descending order, participants marked "long-term survival" as the highest priority with a score of 4.21, followed by "risk of adverse events/side effects" (3.72), "dosing schedule/logistics" (3.08), "lifestyle and family implications" (2.84), and "financial concerns" (1.30). As 75% of participants marked financial concerns as their lowest priority, it can be inferred that patients are significantly more concerned with survival and quality of life.

	1	2	3	4	5	TOTAL	SCORE
Dosing schedule/logistics	20.00% 12	20.00% 12	18.33% 11	31.67% 19	10.00% 6	60	3.08
Long-term survival	61.29% 38	14.52% 9	12.90% 8	6.45% 4	4.84% 3	62	4.21
Risk of adverse events/side effects	18.03% 11	45.90% 28	29.51% 18	3.28% 2	3.28% 2	61	3.72
Financial concerns	0.00% 0	1.67% 1	1.67% 1	21.67% 13	75.00% 45	60	1.30
Lifestyle and family implications	4.92% 3	19.67% 12	34.43% 21	36.07% 22	4.92% 3	61	2.84

Figure 15: Please rank the following factors by level of importance to you when creating a treatment plan, with 1 being the most important.

Question 18: Do you feel the factors listed in the previous question (dosing schedule/logistics, long term survival, risk of adverse events/side effects, lifestyle and family implications) were adequately considered when creating a treatment plan with your healthcare team?

Following up on question 17, question 18 asked participants whether they feel that their healthcare team addressed these considerations (dosing schedule/logistics, long term survival, risk of adverse events/side effects, lifestyle and family implications) when developing their treatment plan. 62.50% felt that "yes," these concerns were addressed; 21.88% that they were "somewhat" addressed; 8.38% that "no," they were not addressed; and 1.56% "don't recall." 4.69% selected "other" and added comments; while two of these indicated that their cancer was at too early a stage to require treatment, one comment noted that the severity of their side effects has made them question the treatment course selected by their healthcare team. This latter response highlights the disparity that can arise between patient and physician expectations regarding side effect tolerability.

ANSWER CHOICES	RESPONSES	
Yes	62.50%	40
Somewhat	21.88%	14
No	9.38%	6
Don't recall	1.56%	1
Other (please specify)	4.69%	3
TOTAL		64

Figure 16: Do you feel the factors listed in the previous question (dosing schedule/logistics, long term survival, risk of adverse events/side effects, lifestyle and family implications) were adequately considered when creating a treatment plan with your healthcare team?

Question 19: Which members of your healthcare team were involved in your treatment decision-making process? Their roles or titles are adequate to answer this question.

This question asked participants which members of their healthcare team were involved in their decision-making process. Excluding responses which did not offer at least one medical title, 59 people answered this question. When viewing this data, please note that the survey population was mixed between melanoma, NMSC, and ocular melanoma patients, meaning that it does not accurately represent statistics for one of these groups. Further, some of these responses are difficult to parse given the lack of commas.

Participants most frequently mentioned medical oncologists as contributors to their medical decision-making (31; 52.54%). In descending order, this was followed by general practitioners (17; 28.81%), surgeons (11; 18.64%), dermatologists (eight; 13.56%), ocular oncologists (six, 10.17%), radiologists or radiation oncologists (six; 10.17%), nurses (five; 8.47%), plastic surgeons (four; 6.78%), and surgical oncologists (2; 3.39%).

Question 20: What information do you feel would have enabled you to best understand the conversations surrounding your treatment plan? Write in your answers.

Question 20, which accrued 63 responses, asked participants what further information they would have liked to receive to help them better understand their treatment plan. The most frequent response was that participants had the information they required (18; 28.57%). Following this, participants would have liked more information about what to expect in terms of adverse events/side effects (nine; 14.29%), followed by having more knowledge of treatment options (three; 4.76%), meeting with a melanoma oncologist (three; 4.76%), prefer written information (three; 4.76%), and receiving more information about causes of melanoma, survival statistics, and follow-up procedures, and having more conversations with their healthcare team were all mentioned twice (3.17% each). Having a more thorough walkthrough of their treatment plan, a copy of their pathology report, more information about biopsy results, a more coordinated effort by their healthcare teams, a greater understanding of the implications of their first-line treatment on future treatment options, staging, recurrence, having more medical opinions, efficacy of treatment, and prognosis were each mentioned once (1.59% each). One response noted that they still feel like they haven't received an adequate amount of information and another that the information landscape has improved since their diagnosis in 1984.

Question 21: On this scale, how satisfied were you by the level and quality of information offered to you after diagnosis?

Here, participants were asked to rank the quality of information they were offered after their initial diagnosis on a scale from "I was dissatisfied with the amount and quality of information I received after diagnosis" to "I was completely satisfied with the amount and information I received." Most responses indicated that they were satisfied with the information they received, with 18.13% voting that they were "completely satisfied with the amount and quality of the information [they] received" and another 28.13% were "pretty satisfied with the amount and quality of information [they] received." Moving towards the negative end of the scale, 10.94% reported being "neutral about the amount and quality of the information [they] received," 23.44% "would have liked more and/or better quality information, but [were] not entirely dissatisfied," and 9.38% were "dissatisfied with the amount and quality of information [they] received." Overall, this feedback is positive, though there is clearly a significant population who, whether due to location or other circumstances, are not accessing adequate information.

	I WAS DISSATISFIED WITH THE AMOUNT AND QUALITY OF INFORMATION I RECEIVED AFTER DIAGNOSIS	I WOULD HAVE LIKED MORE AND/OR BETTER QUALITY INFORMATION, BUT WAS NOT ENTIRELY DISSATISFIED	I WAS NEUTRAL ABOUT THE AMOUNT AND QUALITY OF THE INFORMATION I RECEIVED	I WAS PRETTY SATISFIED WITH THE AMOUNT AND QUALITY OF INFORMATION I RECEIVED	I WAS COMPLETELY SATISFIED WITH THE AMOUNT AND INFORMATION I RECEIVED	TOTAL	WEIGHTED AVERAGE
☆	9.38% 6	23.44% 15	10.94% 7	28.13% 18	28.13% 18	64	3.42

Figure 17: On this scale, how satisfied were you by the level and quality of information offered to you after diagnosis?

Question 22: How consistent was the information you received during the care planning process?

Question 22 assessed the consistency of information participants received during the planning process. 50% of participants indicated that the information they received while making treatment decisions was "very consistent." 32.81% reported that the information they received was "mostly consistent," 10.94% received "somewhat consistent" information, and 6.25% said the information they received was "not consistent."

ANSWER CHOICES	RESPONSES	
Very consistent	50.00%	32
Mostly consistent	32.81%	21
Somewhat consistent	10.94%	7
Not consistent	6.25%	4
TOTAL		64

Figure 18: How consistent was the information you received during the care planning process?

Question 23: When selecting a treatment, did your oncologist explain the following treatment options to you? Check all that apply (note: responses to this question will be assessed against diagnosis date to confirm whether all treatment options were available at the time of diagnosis).

This question asked what treatment options participants were offered when they were selecting a first-line treatment. The most common option offered was "surgery," as indicated by 75% of participants. This was followed in frequency by "immunotherapy" (48.44%), "radiation" (37.50%), "targeted therapy" (17.19%), and "chemotherapy" (9.38%). 20.31% of participants selected "other" and added more information about their circumstances and what treatments they were offered, the most frequent of these being clinical trials (four mentions).

This data is consistent with the years of diagnosis offered in question five. Surgical options have always been a popular first-line choice for melanoma and NMSC. The lower rates of chemotherapy relative to slightly higher votes for targeted therapy, and significantly higher for immunotherapy are also consistent with the years of diagnosis, as 49 out of 63 participants were diagnosed in 2011 or later. 2011 corresponds with the increased usage of immunotherapy for melanoma, and the targeted therapies for melanoma, trametinib, cobimetinib, and binimetinib were approved in 2013, 2015, and 2018 respectively.

ANSWER CHOICES	RESPONSES	
Immunotherapy	48.44%	31
Targeted therapy	17.19%	11
Surgical options	75.00%	48
Radiation	37.50%	24
Chemotherapy	9.38%	6
Other (add other treatment option(s) offered to you)	20.31%	13
Total Respondents: 64		

Figure 19: When selecting a treatment, did your oncologist explain the following treatment options to you? Check all that apply

Question 24: On this scale, please indicate how prepared you felt for treatment based on the information you were given?

This question asked participants how prepared they felt for treatment on a scale from feeling "completely unprepared for treatment" to "entirely prepared for treatment." The largest portion of participants felt "adequately" prepared for treatment (46.88%) while only 15.63% felt "entirely" prepared for treatment. Moving back down the scale to less prepared, 17.19% felt "adequately prepared for treatment, but could have been more prepared," 15.63% felt "mostly unprepared for treatment," and 4.96% felt "completely unprepared for treatment." This data demonstrates that patients are generally well-primed for treatment, however the unpredictability of side effects can make it difficult to entirely prepare.

	I FELT COMPLETELY UNPREPARED FOR TREATMENT	I FELT MOSTLY UNPREPARED FOR TREATMENT	I FELT ADEQUATELY PREPARED FOR TREATMENT, BUT COULD HAVE BEEN MORE PREPARED	I FELT ADEQUATELY PREPARED FOR TREATMENT	I FELT ENTIRELY PREPARED FOR TREATMENT	TOTAL	WEIGHTED AVERAGE
☆	4.69% 3	15.63% 10	17.19% 11	46.88% 30	15.63% 10	64	3.53

Figure 21: On this scale, please indicate how prepared you felt for treatment based on the information you were given?

Question 25: Has your level of knowledge about melanoma changed since your diagnosis?

Question 25 asked participants whether they feel their level of melanoma-related knowledge has changed since their diagnosis. Perhaps predictably, most participants felt that their knowledge of melanoma has changed "substantially" since diagnosis (81.25%). 12.50% said that their knowledge of melanoma has changed "a bit," and 6.25% said that "no," their knowledge has not changed. Participants mentioning in previous comments that they feel they haven't gotten any information, or that they have not received new information due to working in the medical field before their diagnosis, might account for this latter figure.

ANSWER CHOICES	RESPONSES	
Yes, substantially	81.25%	52
Yes, a bit	12.50%	8
No, it has not	6.25%	4
TOTAL		64

Figure 22: Has your level of knowledge about melanoma changed since your diagnosis?

Question 26: If your knowledge of melanoma has increased, from where did you gain this new information? Check all that apply.

This question asked participants to indicate from which sources they have gained new information. The most frequently selected source was "the internet" (72.58%), followed by their "medical team" (56.45%), and "patient group(s)" (43.55%). 24.19% of participants selected "other" and added additional comments. These cited friends or family members with medical knowledge or melanoma experience (three mentions), specific patient groups such as SYSF (two mentions), and reading medical articles (six mentions).

ANSWER CHOICES	RESPONSES	
The internet	72.58%	45
Your medical team	56.45%	35
Patient group(s)	43.55%	27
Other (please specify)	24.19%	15
Total Respondents: 62		

Figure 23: If your knowledge of melanoma has increased, from where did you gain this new information? Check all that apply.

Question 27: Select the top TWO challenges you faced during treatment. You also have the option to write in another response.

Question 27 asked participants to select which two of the following challenges were most pressing during their treatment: the need for "emotional support," their "physiological symptoms (of cancer or treatment)," "financial challenges," "lack of information," and "other" challenges they could clarify in the comments. Notably, the most frequently cited challenge was the need for "emotional support," which was selected by 60.94% of participants. This highlights the importance of patient groups and other organizations that coordinate support groups. In descending order, 45.31% selected "physiological symptoms," 21.88% "lack of information," and 12.50% "financial challenges." In the "other" section, most responses reiterated challenges that were contained by the selectable options; however, new challenges included consistency of care (two mentions) and not having treatment available in their area (two mentions).

ANSWER CHOICES	RESPONSES	
Emotional support	60.94%	39
Physiological symptoms (of cancer or treatment)	45.31%	29
Financial challenges	12.50%	8
Lack of information	21.88%	14
Other (please specify)	39.06%	25
Total Respondents: 64		

Figure 24: Select the top TWO challenges you faced during treatment.
You also have the option to write in another response.

Question 28: Please write the ways in which you feel your medical team could have more effectively supported you during your cancer treatments.

This question asked participants how their medical team could have better supported them. There were 59 responses to this question: not all of these directly answered this question, and several responses included multiple suggestions. The most frequent comment was that participants felt well supported by their healthcare team (25 mentions; 42.37%). Other suggestions included being offered a better understanding of what survivorship looks like (six; 10.17%), being able to have proper conversations with their oncologists (three; 5.08%), being offered more treatment options (three; 5.08%), more honesty about side effects (two; 3.39%), a more direct way to contact their oncologist (two; 3.39%), mental health resources (two; 3.39%), more information about patient groups (two; 3.39%), that they could be more prepared with informational resources (one; 1.69%), could have been more compassionate (one; 1.69%), could have been more diligent when confirming efficacy of treatment (one; 1.69%), offered more information about recurrences (one; 1.69%), more expedient follow-up (one; 1.69%), provided more weekend and evening support (one; 1.69%), and more written informational material (one; 1.69%).

Question 29: When you experienced challenges with your cancer treatments, where did you successfully find help? Select all that apply.

Question 29 asked survey participants where they turned for help when they experienced challenges with their cancer treatments, allowing them to select all members of their healthcare team that apply. The most frequently selected option was their "medical oncologist[s]" (46.88%), followed by "friends and family" (37.50%), their "general practitioner" (26.56%), "patient group[s]" (20.31%), and "nurses" (15.63%). 40.63% of participants selected "other" and wrote in additional comments. These outlined their circumstances in more detail and cited more places they have successfully found support, including dermatologists (two), counsellors (two),

pharmacists (one), psychiatrists (one), surgeons (one), optometrists (one), and triage nurses (one).

ANSWER CHOICES	RESPONSES	
Your medical oncologist	46.88%	30
Your general practitioner	26.56%	17
Nurses	15.63%	10
Friends/family	37.50%	24
Patient group	20.31%	13
Other (please specify)	40.63%	26
Total Respondents: 64		

Figure 25: When you experienced challenges with your cancer treatments, where did you successfully find help? Select all that apply.

Question 30: Has your experience with cancer changed how you view the Canadian healthcare system? If yes, please elaborate.

The final question of the survey asked participants whether their experience with cancer changed their perceptions of the Canadian healthcare system. The responses were nearly evenly split, with 56.25% voting that "yes," it did change their view of the Canadian healthcare system and 43.75% indicating that "no," their views did not change. Participants elaborated in the comments. 17 comments mentioned having a positive experience with the healthcare system. Areas participants argued were lacking included longer wait lists than expected (four), more out-of-pocket costs than they were expecting (three), lack of standard of care across hospitals (three), understaffing (three), treatments not being widely available (two), patients having to advocate for themselves too much (two), lack of funding (two), too much bureaucracy (one), not enough resources for rare cancers (one), and limited support in evenings or on weekends (one). This data demonstrates that cancer patients can have a variety of experiences in the Canadian healthcare system and are often surprised by how stretched the system is, especially as the majority of survey participants would have received care during the COVID-19 pandemic, an unprecedented period of stress in global health.

ANSWER CHOICES	RESPONSES	
No, it has not changed the way I view the Canadian healthcare system	43.75%	28
Yes, it has changed the way I view the Canadian healthcare system (please elaborate)	56.25%	36
TOTAL		64

Figure 26: Has your experience with cancer changed how you view the Canadian healthcare system? If yes, please elaborate.

French Language Survey Data

This section of the report will discuss the data from the French language version of the survey, which accrued 11 responses between September 10 to October 24, 2022. 90.91% of the responders identify as "female" and 9.09% as "male," with 36.36% falling between "60-69 years" of age, 27.27% fall into each bracket of "30-49" and "50-59," and 9.90% are "70-79" (Q1; Q2). 81.82% participants reside in "Québec" and 18.18% "elsewhere," though they did not specify (Q3). Like the English survey, the French survey population have largely been diagnosed in the last three years, with four being diagnosed in 2022 (36.36%), two in 2020 (18.18%), and one each in 2019, 2018, 2015, 2010, and 2004 (9.09% each) (Q5).

The initial diagnosis appointments were slightly longer in the French language cohort, with 63.64% of them lasting "15-30 minutes" and 18.18% lasting "30 to 45 minutes" (9.09% did not remember; Q6). Important factors for them to discuss with their healthcare team at the time of diagnosis were ranked in the order of "care plan" (score: 4.55), "prognosis" (3.89), "quality of life" (3.11), "treatment timeline" (2.60), and "financial considerations" (1.11) (Q7). 54.55% felt that these issues were "somewhat" discussed in their diagnosis appointment, 36.36% that "yes," they were discussed, and 9.09% that "no," they were not discussed (Q8). Like the English cohort, treatment plans in the French language cohort were almost exclusively developed "at the time of diagnosis" (45.45%) and "between the first and third visits" (36.36%); 18.18% selected "other" and included more specifics about their experience (Q9). This pace aligns with their ideal treatment plan timeline, as 45.45% would like to create treatment plans "at the time of diagnosis" and 45.45% "between the first and third visits;" 9.09% voted "other" and said they would like this decision to be handled quickly (Q10).

When asked where they received their cancer-related information, 54.55% French language respondents selected their "medical oncologist[s]" and 9.09% "nurse navigators;" keep in mind that these results may be skewed by translation differences in medical titles (Q11). 72.73% selected "other" and added comments, which included surgeons (four mentions), dermatologists (three mentions), the internet (two mentions), and general practitioners (one mention) (Q11). When asked if they understood most of the cancer-related information they received, 36.36% of the survey population voted that they understood "all of the information" and that they understood "most of the information, but not all of it" individually, though approximately one third of this group understood less, with 9.09% responding that they understood "about half" of the information and 18.18% "a little bit" of the information; overall, this is a less positive data set than we saw in the English language cohort (Q12). In question 13, "the internet" was a popular resource for cancer-related information (nine mentions), along with "medical reading" (two mentions), and "patient group(s)" (two mentions). Responses to question 14 indicated that French language participants mostly experienced consistency in their healthcare teams, with 63.64% noting "no changes," 18.18% reporting a "change in their medical oncologist," and 9.09% reporting a "change in their clinic or hospitals;" 9.09% selected "other" and noted that they have seen multiple surgeons.

The survey then shifted to discuss treatment decision-making, wherein the French language participants indicated that they had a much greater level of involvement in their treatment decisions than the English language cohort. In question 15, 27.27% reported that they made their treatment decisions "entirely independently" and 36.36% that they "largely made the decision independently;" only 27.27% felt that they were "appropriately involved" in this decision, and 9.09% that they were "not involved at all" (Q15). Given these figures, it is appropriate that a larger portion (18.18%) felt that "too much" of the decision was left to them in question 16, with a further 9.09% reporting that they "would have liked more guidance," 54.55% that they felt "appropriately involved" in the decision, and 18.18% that they "would have liked to have had a little more input." In question 19, participants mentioned that their oncologists (five mentions), dermatologists (five mentions), oncological surgeons (three mentions), plastic surgeons (three mentions), nurse navigators (two mentions), and surgeons (one mention) as being involved in their treatment decision-making process.

When asked to rank which concerns were of highest priority to them when developing a treatment plan, the French language cohort was most concerned with "long-term survival" (score: 4.55), followed by "risk of adverse events/side effects" (3.89), "dosing schedule/logistics" (3.50), "lifestyle and family implications" (2.22), and "financial concerns" (1) (Q17). In question 18, the majority (72.73%) indicated that "yes," these concerns were discussed in the development of a treatment plan, while 18.18% said they were "somewhat" discussed, and 9.09% said that "no," they were not discussed.

When asked what additional resources would have helped them better understand the cancer-related information they were offered (question 20), responses included more statistics, written documents, more opportunities to ask questions, mental health resources, and more information about risks of recurrence and metastasis were all mentioned once; five responses noted that they would not need to supplement the information they had received. This mostly positive response to the information they were provided carried through question 21, wherein 45.45% indicated that they were "completely satisfied with the amount and quality of the information they received," 27.27% were "pretty satisfied," 9.09% were "neutral," 9.09% "would have liked more and/or better quality information, but [were] not entirely dissatisfied," and 9.09% were "dissatisfied with the amount and quality of information [they] received." This information was also evidently consistent, with 36.36% voting that the information they received was "very consistent," 36.36% for the information being "mostly consistent," and 9.09% "not consistent." The French language cohort offered similar responses to the English regarding cancer-related information sources. As in the English language survey, the majority of participants (81.82%) felt that their knowledge of melanoma has increased since their diagnosis (Q25). In question 26, they cited "the internet" as their most frequently accessed source of melanoma information (81.82%), followed by their "medical team" (54.55%), "patient groups" (9.09%), and "other" (18.18%), which specified internet sites they had visited. The one deviation from the English language cohort here was that the French language group utilized patient groups significantly less (43.55% versus 9.09%).

When asked what treatment options they were offered, the most frequently selected response was "immunotherapy" (54.55%), followed by "surgical options" (45.45%); "targeted

therapy" and "chemotherapy" were tied with 9.09% each (Q23). 27.27% selected "other" and added more details about which of these treatments they were offered. Interesting deviations from this section of the English language survey include a lower rate of surgical options being offered (75% in English) and zero votes for radiation therapy. In question 24, participants were polarized between being "entirely prepared for treatment" (63.64%), "mostly unprepared for treatment" (27.27%), and "completely unprepared for treatment" (9.09%); as the French language results are entirely grouped in these three areas, the voting percentage is also higher in each.

When asked what the top two challenges the French language participants faced during treatment, the French language cohort most frequently voted for "physiological symptoms" (54.55%), followed by "emotional support" (36.36%), "lack of information" (36.36%), and "financial difficulties" (9.09%). Emotional support was a greater concern for the English language cohort, being voted for by 60.94% percent of participants. 27.27% selected "other" and added additional details about their circumstances (Q27). In question 27, some reported having an excellent experience with their healthcare team (four mentions), while a few mentioned that their experience would be improved if their healthcare team had performed more regular follow-ups (three mentions), increased mental health support (one mention), being able to have more conversations with their oncologist (one mention), better listening to reported side effects (one mention), and less contact between treatment (one mention). When asked who they turned to when they were facing challenges in their treatment, 45.45% selected their "medical oncologists," 45.45% "nurses," 36.36% "friends and family," and 27.27% their "general practitioners" (Q29). 45.45% selected "other" and added comments, which included the internet (two mentions) and their dermatologists (two mentions). In question 30, 63.4% of participants noted that "yes," their impressions of the Canadian healthcare system changed after their experience, while 36.36% said that "no," it did not. Comments added to this question included a lack of follow-up care (one mention) and the need to advocate for oneself (one mention); four participants cited receiving excellent care in the Canadian system, though two of these noted that you need to fight to be integrated enough into the system to receive this standard of care.

Differences between the English and French language cohorts include an increased independence when making treatment decisions in the French cohort and a related dissatisfaction with the lack of guidance (Q15), the lack of patient group utilization in the French cohort (Q26), and surgical care options being offered less to the French cohort, and radiation not at all (Q23). As nurses were not mentioned as a source of information whatsoever in the French language survey results, they occupy a less pedagogical role in the medical systems of the French-speaking provinces (Q11). The English language cohort reported a higher need for emotional support in question 27, which is interesting given their higher rate of patient group contact in question 26. In question seven, the English language group listed prognosis as the most important concern when developing a treatment plan, while the French language population ranked treatment timeline more highly. Taken together, these differences indicate that there has been less guidance offered to the French language participants.

Patient Versus Physician Data

Comparing the results of the patient and physician surveys illuminates both similarities and differences in these perspectives. For example, questions 9 (physician survey) and 11 (patient survey) indicates that both patients and oncologists see medical oncologists as the primary source of information and education for patients. Questions 11 (physician) and 12 (patient) elaborated on the topic of patient information, and the data suggests that patients understand the information they are given at a roughly consistent rate to what oncologists expect. Comparing question 5 (physician) and question 15 (patient) also highlights that oncologists and patients have relatively similar expectations of patient involvement in the treatment decision-making process, though this varies from patient-to-patient.

There were also some notable discrepancies between the physician and patient survey results. The first of these can be seen in question 3 (physician) and 6 (patient), in which the majority of oncologists stated that the average initial diagnosis appointment lasts at least 45 minutes, whereas 69.83% of participants stated that their diagnosis appointment lasted less than 45 minutes, with 33.33% indicating that the appointment was 15 minutes or less. This difference might also be related to the difference in physician perspective, when they are so often stretched for time, versus the patient, who wants as much time and information as possible.

Conclusion

While conclusions offered by individual data sets appear in those responses, the overall data presented by this survey highlights a variety of successes in Canadian cancer care, while also demonstrating that not all patients benefit from these successes. One success is the speed at which a treatment plan was developed for the participants across both surveys (Q9); yet, in both the English and French language cohorts, there were portions of the survey population who did not understand much of the cancer-related information they received, a population that was especially high in the French language cohort (Q12). Thankfully, the survey responses include a variety of actionable suggestions regarding improved information dissemination and ways that the medical system can further support cancer patients. We thank you for taking the time to read this report.