



Survey Results: *Patient Survey on New Therapy: Opdivo + Yervoy in combination, for treatment-naïve adult patients with advanced (unresectable or metastatic) melanoma, regardless of BRAF status*

From 28 November, 2016 to 25 April, 2017, the Save Your Skin Foundation held the survey *Patient Survey on New Therapy: Opdivo + Yervoy in combination, for treatment-naïve adult patients with advanced (unresectable or metastatic) melanoma, regardless of BRAF status* for treatment-naïve adult patients with melanoma skin cancer who had undergone the combination therapy of Opdivo + Yervoy. The Save Your Skin Foundation is a Vancouver, Canada-based skin cancer not-for-profit patient group, which works to improve patient access to innovative medicines, such as the Opdivo + Yervoy combination therapy, as part of its mandate. More information about the Save Your Skin Foundation can be found at [www.saveyourskin.ca](http://www.saveyourskin.ca).

Participants had to have advanced (unresectable or metastatic) melanoma, and their BRAF status was not taken into account for this survey. Of the survey participants, 57% were female and 43% were male<sup>1</sup> (answered: 58, skipped: 2), and the majority of participants were between 50-59 years of age (31%) followed by 60 or older (29%), 40-49 years of age (19%), 30-39 years of age (16%), and 21-29 years of age (5%)<sup>2</sup> (answered: 58, skipped: 2). Of the survey participants, 47% described themselves as having full time employment, 32% are retired, 8% are working part-time or unable to work due to disability, 4% are unemployed but looking for work, and 2% are unemployed and not looking for work<sup>3</sup> (answered: 53, skipped: 7). 42% of survey participants are located outside of Canada (largely being located in the United States of America (76%) or the United Kingdom (24%)<sup>4</sup> (answered: 21, skipped: 39)), the majority of Canadian participants were from British Columbia (32%), Ontario (9%), and Québec (8%)<sup>5</sup> (answered: 53, skipped: 7).

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<sup>1</sup> Statistics retrieved from Save Your Skin Foundation Question 1.

<sup>2</sup> Statistics retrieved from Save Your Skin Foundation Question 2.

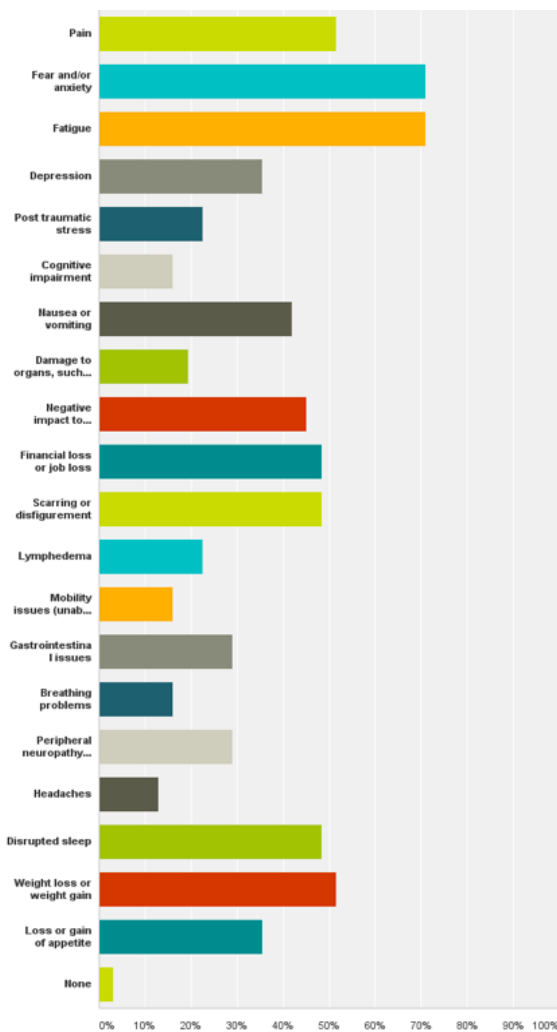
<sup>3</sup> Statistics retrieved from Save Your Skin Foundation Question 3.

<sup>4</sup> Statistics retrieved from Save Your Skin Foundation Question 5.

<sup>5</sup> Statistics retrieved from Save Your Skin Foundation Question 4.



After establishing participant demographics, the survey questions addressed the participants' experiences with melanoma and the Opdivo + Yervoy combination therapy. Question 6, "Cancer and the different stages of cancer affect people in different ways. What issues have you experienced with the cancer itself? Please select as many responses as appropriate" (answered: 21, skipped: 39) catalogued participants physical and mental reactions to cancer. Feelings of fear and/or anxiety (72%) and fatigue (72%) were the top responses<sup>6</sup>. A further breakdown of the physical and mental effects survey participants associated with their cancer can be found in figure 1.



<sup>6</sup> Statistics retrieved from Save Your Skin Question 6.



Figure 1

Question 7: “In relation to the symptoms you may have indicated above, how did these or do these symptoms affect your day to day life? What, if any, problems have affected your life quality of life as a result of having melanoma?” (answered: 27, skipped: 33) further addressed the symptoms suggested in question 6, specifically how these complications affected survey participants in their daily lives.

Participants frequently reported fatigue that impacted their social, familial, or professional lives (12 comments), anxiety (8 comments), impaired cognitive ability (4 comments), and pain (2 comments)<sup>7</sup>.

When asked in question 8, “In your opinion, which symptoms of the disease are most important to control?” (answered: 26, skipped: 34), the most frequent responses were related to anxiety (7 comments), metastasis (6 comments), pain (6 comments), and fatigue (5 comments)<sup>8</sup>.

Question 9: “what other therapies have you been treated with for your melanoma?” (answered: 29, skipped: 31) assessed which therapies survey participants had undergone other than the Opdivo + Yervoy combination, with Yervoy (Ipilimumab) (62%), Interferon (41%), and PD1 (Nivolumab or Keytruda) (34%) comprising the majority of the results<sup>9</sup>. A further list of treatments received by survey participants is available in figure 2, located on page 4 of this report. Other responses not featured include DCIT and Temazolmide.

Patients were asked what having a variety of options meant to them in question 10: “if you were treated previously with Opdivo or Yervoy as single agents, or any other drug therapy, and still had recurrence of your disease, what would having access to other new drug therapies mean to you?” (answered: 18, skipped: 42). Of the 18 comments, hope for survival was mentioned 8 times, making it the most frequent answer<sup>10</sup>.

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<sup>7</sup> Statistics retrieved from Save Your Skin Question 7.

<sup>8</sup> Statistics retrieved from Save Your Skin Question 8.

<sup>9</sup> Statistics retrieved from Save Your Skin Question 9.

<sup>10</sup> Statistics retrieved from Save Your Skin Question 10.

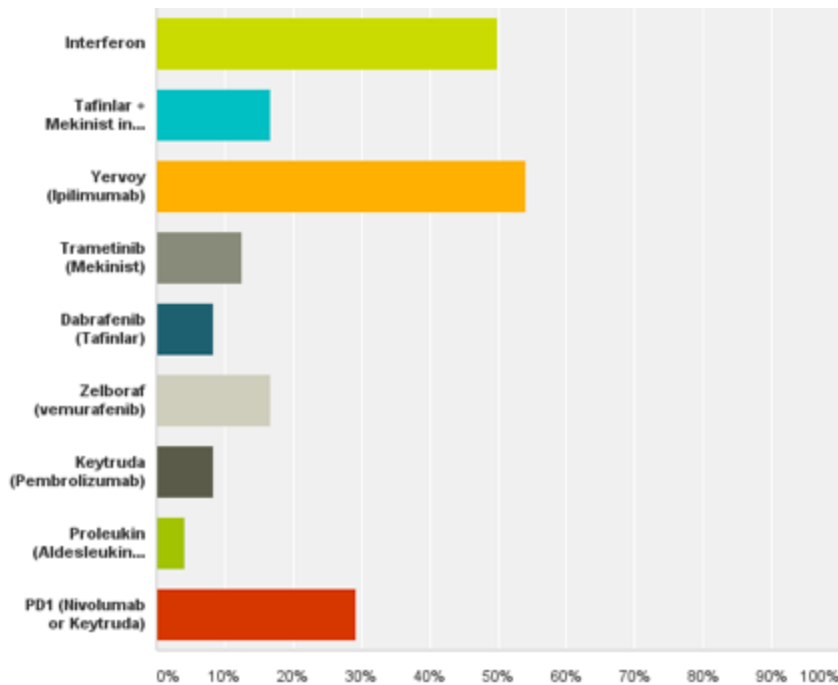


Figure 2

The answers to question 11, “how has having a diagnosis affected your family or a primary caregiver? What challenges, if any, has your spouse, partner, or other caregiver or family member experienced that has impacted their daily routine or lifestyle?” (answered: 29, skipped: 31) demonstrated the overwhelming emotional turmoil of a cancer diagnosis, with the depression, fear, or anxiety appearing in 17 of 29 comments. 8 other comments suggested a change in family dynamics<sup>11</sup>.

Question 12: “while receiving the medication Opdivo + Yervoy regimen infusions to control or eliminate your disease, what side effects (if any) of the treatment did you or are you experiencing?” (answered: 23, skipped: 37) directly addressed the side effects survey participants experienced while receiving the Opdivo + Yervoy combination therapy. The three most frequent responses were fatigue or

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<sup>11</sup> Statistics retrieved from Save Your Skin Question 11.



weakness (74%), skin rash (57%), and muscle or joint pain (39%)<sup>12</sup>; further responses can be viewed in figure 3. Responses not present in the graph include vitiligo, irregular heartbeat, and low white blood cell count<sup>13</sup>.

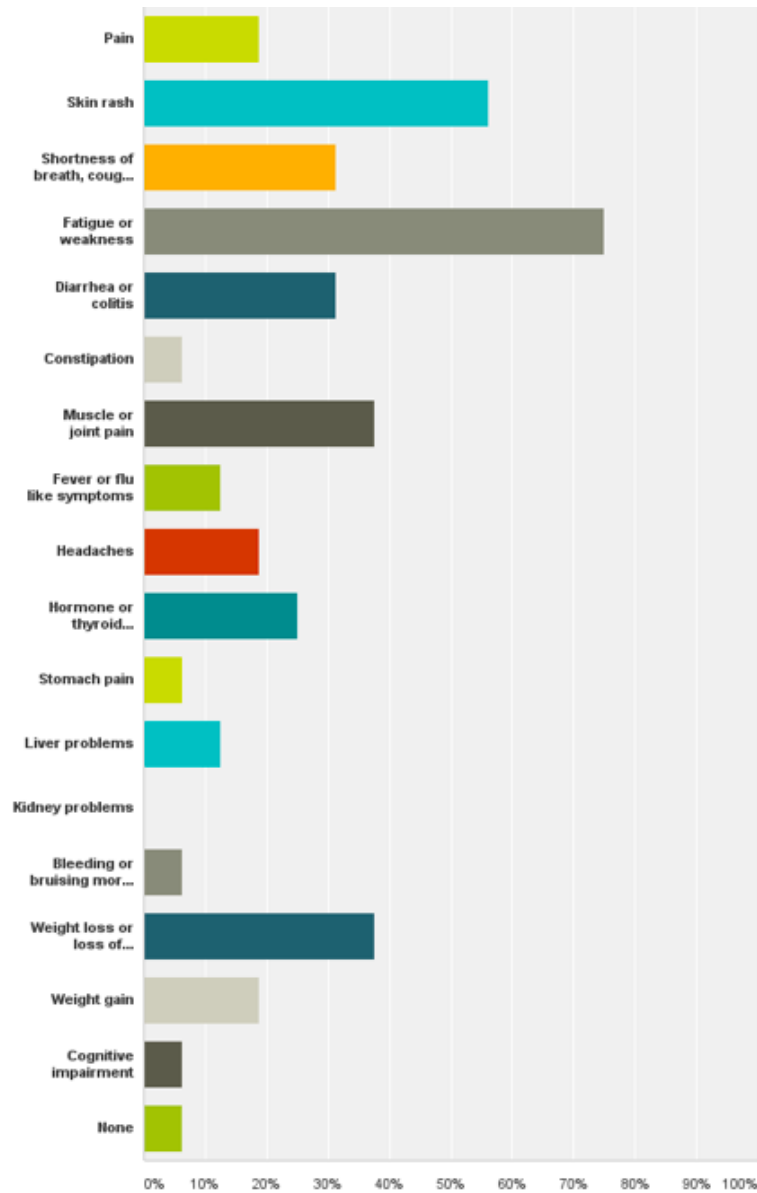


Figure 3

<sup>12</sup> Statistics retrieved from Save Your Skin Question 12.

<sup>13</sup> Save Your Skin Question 12.



When asked in Question 13, “were the side effects of the treatment manageable?” (answered: 20, skipped: 40), 85% of participants replied that side effects were manageable, while 15% replied that side effects of the treatment were not manageable<sup>14</sup>. Further, 85% of participants responded positively to Question 14, “In your opinion, if you experienced side effects, did the benefits of the treatment outweigh the experience of the side effects?” (answered: 20, skipped: 40), while 15% responded negatively<sup>15</sup>. Question 15: “has the combination treatment Opdivo + Yervoy improved your quality of life? If ‘yes,’ please explain what benefit you have had. If ‘no,’ please explain” (answered: 21, skipped: 39) saw 71% positive responses, and participants claimed that their quality of life had been improved by successful treatment, which allowed them increased engagement with their daily lives and provided hope of survival to themselves and their caregivers. 29% of participants did not express having a greater life quality, generally remarking in the comments that they were currently undergoing treatment and the side effects (mainly fatigue) were difficult to manage<sup>16</sup>.

To question 16: “what has been the outcome of the combination treatment Opdivo + Yervoy for you?” (answered: 19, skipped: 41), 37% of participants reported that the treatment had slowed progression of their cancer; another 37% stated that their cancer had been eliminated, and they were presently cancer free; 16% found that their treatment created additional health issues or lingering side effects; and 11% were unaffected by the treatment<sup>17</sup>. A further 8 participants revealed in the comments that they had skipped this question as their treatment was still in progress, though all of the commenters felt that their treatment was promising.

Question 17 asked “if you had a full response to treatment, how long has it been since you were treated?” (answered: 13, skipped: 47). 54% of responders had been treated within six months of taking the

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<sup>14</sup> Statistics retrieved from Save Your Skin Question 13.

<sup>15</sup> Statistics retrieved from Save Your Skin Question 14.

<sup>16</sup> Statistics retrieved from Save Your Skin Question 15.

<sup>17</sup> Statistics retrieved from Save Your Skin Question 16.



survey; 15% over six months, but less than one year; 23% over one year, but less than two; and 8% had experienced progression of their cancer since treatment<sup>18</sup>.

The next section of the survey addressed the impact of the Opdivo + Yervoy combination on patient's lives, beginning with question 18: "did you experience any hardships accessing the treatment? Was the treatment readily available to you? [...] Please explain" (answered: 18, skipped 42). Of the 18 responses, 9 replied that they did not experience hardships in accessing the trial. 2 responses stated that they experienced financial hardships, 2 reported that they had to travel long distances to their trial, and 1 mentioned a long wait to get into their trial (in 2013)<sup>19</sup>. Question 19 asked participants: "what does your spouse, family member, and/or caregiver say about the impact of this drug on their daily life? Has it had an impact (positive or negative) on them?" (answered: 18, skipped: 42). Of the 18 responses, 11 reported that their successful treatment has positively impacted their caregivers, spouses, and/or families. Other responses include caregivers experiencing anxiety over side effects, and spouses having to work more to ease financial stress or manage the household<sup>20</sup>.

Questions 20 and 21 ascertained the treatment history of the survey participants. Question 20 "Did you complete full course of treatment? If not, explain why" (answered: 21, skipped: 39) yielded 67% negative results and 33% positive results. Of the 17 comments, 10 revealed that participants were still undergoing treatment at the time of the survey, while 4 commenters were removed from the trial due to negative side effects<sup>21</sup>. Question 21 asked: "are you currently on any other treatments for melanoma or other medical conditions?" (answered: 24, skipped: 36); 83% were not receiving other treatments, while 17% were. Other medications and health concerns included chemotherapy (1 comment), pulmonary

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<sup>18</sup> Statistics retrieved from Save Your Skin Question 17.

<sup>19</sup> Statistics retrieved from Save Your Skin Question 18.

<sup>20</sup> Statistics retrieved from Save Your Skin Question 19.

<sup>21</sup> Statistics retrieved from Save Your Skin Question 20.



hypertension and asthma (1 comment), upcoming surgery (1 comment), and treatment-induced endocrine and pancreatic issues (2 separate comments)<sup>22</sup>.

When asked about their expectations and hopes for cancer treatments, the survey participants had a variety of answers. When asked in question 22 “if you could describe what you as a patient are looking for in new treatments coming to market, what would you say?” (answered: 22, skipped: 38), participants consistently cited efficacy (15 comments), minimal side effects (4 comments), and access (4 comments)<sup>23</sup>. The final survey question, question 23: “what are important values to you when hearing of or trying a new treatment [...]?” (answered: 23, skipped: 37) documented what patients valued in new treatments. Frequent responses included quality of life (15 comments), manageable side effects (11 comments), efficacy (6 comments), and access (2 comments)<sup>24</sup>.

While many survey participants are still undergoing treatment, survey results suggest that, despite the margin of side effects, the treatment has reduced cancer in 74% of participants and improved quality of life for 71%. The comment responses indicate that while there is room for improvement, largely in access and side effect management, patients are optimistic about the future of innovative cancer medicines, including immunotherapies such as the Opdivo + Yervoy combination.

More information regarding survey results can be obtained from the Save Your Skin Foundation.

#### Citations:

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<sup>22</sup> Statistics retrieved from Save Your Skin Question 21.

<sup>23</sup> Statistics retrieved from Save Your Skin Question 22.

<sup>24</sup> Statistics retrieved from Save Your Skin Question 23.



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Save Your Skin Foundation. *Patient Survey on New Therapy: Opdivo + Yervoy in combination, for treatment-naïve adult patients with advanced (unresectable or metastatic) melanoma, regardless of BRAF status*. 28 November, 2016 - 25 April, 2017. SurveyMonkey. Web.