Cancer Survivorship Survey

Findings from an Online Survey of Adult Cancer Patients

January 2019
To explore experiences and needs surrounding cancer survivorship across a range of cancer patients.

• Profile respondents on various dimensions (type of cancer, stage, treatment/s, side effects, demographics, etc.), to understand differences by key audiences

• Identify the most frequent and severe side effects, and where patients need help

• Understand what assistance patients need in post-treatment information and care

• Learn more about information sources, and where gaps exist today
Survey Methodology

Online Survey of 1,380 cancer patients
• Completed Treatment: n=688 patients
• In-Treatment for Initial Diagnosis: n=388 patients
• In-Treatment for Recurrence: n=258 patients
• Metastatic Cancer: n=166 patients
• Immunotherapy: n=262 patients*

Distributed by NCCS and 9 partner cancer advocacy/care organizations
• 56% from NCCS e-mail and social media
• 10% Cancer Care
• 9% Fight Colorectal Cancer
• 4% Melanoma Research Alliance; Ovarian Cancer Alliance
• 3% Livestrong; Melanoma Research Foundation
• 2% Supporting Our Sisters Inc.
• 1%: Cancer Support Community; LUNGevity

Survey Note:
• The survey instrument was peer reviewed by NCCS staff and other experts in the field.
• As with all online surveys, this survey uses a convenience sample of respondents drawn from multiple channels. As such, findings are not generalizable to the cancer population as a whole.

*Note: N=101 patients with either breast, brain, prostate, liver, pancreatic or myeloma cancer indicated they had received immunotherapy. These respondents were removed from this audience for analysis, as there were no immunotherapy products with FDA-approved indications for these cancers at the time the survey was conducted.

Blue (higher) / Red (lower) indicates statistical significance across 3 or more key audiences
Executive Summary

**Treatment Experiences**

- Patients report many physical and emotional side effects. Fatigue and anxiety top the list of both the most common and long term effects. These are also among the most severe side effects reported by patients.

- However, patients report that while healthcare providers are helpful at addressing their physical side effects such as nausea and vomiting, HCPs are far less helpful at addressing fatigue, anxiety, depression and cognitive effects.

**Post-Treatment Information and Care**

- Few feel very prepared for the transition to post-treatment, nor informed about how to manage their health post-treatment.

- While most patients have spoken to a healthcare provider about post-treatment care, over half say they asked their doctor/HCP, and far fewer say their provider initiated these conversations.

- Satisfaction with post-treatment care is varied, with few describing it as excellent. As a result, more rely on online sources for information rather than their HCPs.
Executive Summary

**Survivorship Needs**

- When asked to identify their level of concern about a range of issues, financial issues tops the list (getting/keeping health insurance, having financial support), followed by managing ongoing side effects, uncertainty about the future, and having the energy to make it through the day.

- There is clearly a disconnect between patient concerns and support from HCPs. Less than a third rate their HCP as “very helpful” on their top issues.

- Many are interested in survivorship resources, especially programs for managing long-term symptoms, but few say these are available from the HCPs today.
Treatment Experiences
Patients report many physical and emotional side effects

- Feeling overly tired and anxiety are most common and long lasting.

### Symptoms during/following treatment and today

<table>
<thead>
<tr>
<th>Symptom</th>
<th>During/after treatment</th>
<th>Still experiencing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling overly tired</td>
<td>41%</td>
<td>67%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>40%</td>
<td>58%</td>
</tr>
<tr>
<td>Nausea/vomiting or diarrhea</td>
<td>18%</td>
<td>49%</td>
</tr>
<tr>
<td>Muscle/joint pain</td>
<td>25%</td>
<td>45%</td>
</tr>
<tr>
<td>Depression</td>
<td>28%</td>
<td>44%</td>
</tr>
<tr>
<td>Memory loss, cognitive issues</td>
<td>31%</td>
<td>43%</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>26%</td>
<td>38%</td>
</tr>
<tr>
<td>Dermatological problems</td>
<td>13%</td>
<td>33%</td>
</tr>
<tr>
<td>Uncertainty around status of your cancer</td>
<td>13%</td>
<td>31%</td>
</tr>
<tr>
<td>Fever/chills</td>
<td>9%</td>
<td>28%</td>
</tr>
<tr>
<td>Bone, joint, and soft tissue issues</td>
<td>15%</td>
<td>27%</td>
</tr>
<tr>
<td>High or low blood pressure</td>
<td>11%</td>
<td>23%</td>
</tr>
<tr>
<td>Uncertainty around when to stop or how long to continue therapy</td>
<td>11%</td>
<td>18%</td>
</tr>
<tr>
<td>Lymphedema</td>
<td>12%</td>
<td>18%</td>
</tr>
<tr>
<td>Endocrine issues</td>
<td>11%</td>
<td>16%</td>
</tr>
<tr>
<td>Respiratory issues</td>
<td>7%</td>
<td>14%</td>
</tr>
<tr>
<td>Cardiac issues</td>
<td>5%</td>
<td>9%</td>
</tr>
</tbody>
</table>

5.65 side effects reported on average

Anxiety & Depression Higher Among:
- Income <$50k: 70%, 62%
- Medicaid: 63%, 53%
Immunotherapy patients report lower incidence of side effects

- Metastatic cancer patients reported more side effects on average and at a higher frequency.

### Symptoms during/following treatment

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Completed TX</th>
<th>In TX (Initial)</th>
<th>In TX (Recurrence)</th>
<th>Metastatic</th>
<th>Immuno-therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling overly tired</td>
<td>67%</td>
<td>75%</td>
<td>62%</td>
<td>52%</td>
<td>81%</td>
<td>43%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>58%</td>
<td>64%</td>
<td>55%</td>
<td>44%</td>
<td>64%</td>
<td>42%</td>
</tr>
<tr>
<td>Nausea/vomiting or diarrhea</td>
<td>49%</td>
<td>49%</td>
<td>51%</td>
<td>45%</td>
<td>64%</td>
<td>36%</td>
</tr>
<tr>
<td>Muscle/joint pain</td>
<td>45%</td>
<td>52%</td>
<td>34%</td>
<td>41%</td>
<td>63%</td>
<td>31%</td>
</tr>
<tr>
<td>Depression</td>
<td>44%</td>
<td>48%</td>
<td>47%</td>
<td>31%</td>
<td>44%</td>
<td>27%</td>
</tr>
<tr>
<td>Memory loss, cognitive issues</td>
<td>43%</td>
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<td>32%</td>
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<td>62%</td>
<td>25%</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>38%</td>
<td>45%</td>
<td>27%</td>
<td>35%</td>
<td>65%</td>
<td>23%</td>
</tr>
<tr>
<td>Uncertainty around cancer status</td>
<td>31%</td>
<td>32%</td>
<td>30%</td>
<td>31%</td>
<td>32%</td>
<td>28%</td>
</tr>
<tr>
<td>Fever/chills</td>
<td>28%</td>
<td>27%</td>
<td>35%</td>
<td>23%</td>
<td>34%</td>
<td>27%</td>
</tr>
<tr>
<td><strong>Average Symptoms Reported</strong></td>
<td>5.65</td>
<td><strong>6.13</strong></td>
<td>5.15</td>
<td>5.08</td>
<td><strong>7.04</strong></td>
<td>4.04</td>
</tr>
</tbody>
</table>

*Top 5 side effects “experienced” by audience*
Patients in treatment for initial diagnosis report greater severity of side effects

- Feeling overly tired is among the most severe side effects across all audiences.

### % who say very severe among those who have (n sizes vary)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Total</th>
<th>Completed TX</th>
<th>In TX (Initial)</th>
<th>In TX (Recurrence)</th>
<th>Metastatic</th>
<th>Immuno-therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling overly tired</td>
<td>37%</td>
<td>37%</td>
<td>40%</td>
<td>37%</td>
<td>33%</td>
<td>39%</td>
</tr>
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<td>44%</td>
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<td>18%</td>
<td>31%</td>
</tr>
<tr>
<td>Endocrine issues</td>
<td>29%</td>
<td>30%</td>
<td>22%</td>
<td>33%</td>
<td>39%</td>
<td>27%</td>
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<td>16%</td>
<td>23%</td>
</tr>
<tr>
<td>Bone, joint, and soft tissue issues</td>
<td>24%</td>
<td>22%</td>
<td>26%</td>
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<td>26%</td>
<td>22%</td>
</tr>
<tr>
<td>Dermatological problems</td>
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<td>12%</td>
<td>44%</td>
<td>13%</td>
<td>4%</td>
<td>21%</td>
</tr>
<tr>
<td>Cardiac issues</td>
<td>22%</td>
<td>20%</td>
<td>27%</td>
<td>29%</td>
<td>26%</td>
<td>30%</td>
</tr>
<tr>
<td>Muscle/joint pain</td>
<td>22%</td>
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<td>18%</td>
<td>21%</td>
<td>15%</td>
<td>30%</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>21%</td>
<td>25%</td>
<td>17%</td>
<td>10%</td>
<td>23%</td>
<td>15%</td>
</tr>
</tbody>
</table>

**Average “Very Severe”**

- 24% for Total
- 22% for Completed TX
- 30% for In TX (Initial)
- 22% for In TX (Recurrence)
- 22% for Metastatic
- 22% for Immuno-therapy

**Top 5 “very severe” by audience**
Healthcare teams are helpful for physical, less helpful for emotional side effects

- With the exception of memory loss/cognitive issues, most say their HCPs are at least “somewhat” helpful at addressing their symptoms; far fewer report HCPs are “very” helpful.

% very/somewhat helpful in addressing

- Nausea/vomiting or diarrhea: 51% very helpful, 39% somewhat helpful
- Cardiac issues: 44% very helpful, 41% somewhat helpful
- High or low blood pressure: 44% very helpful, 38% somewhat helpful
- Endocrine issues: 38% very helpful, 43% somewhat helpful
- Dermatological problems: 41% very helpful, 39% somewhat helpful
- Fever/chills: 40% very helpful, 40% somewhat helpful
- Respiratory issues: 35% very helpful, 44% somewhat helpful
- Lymphedema: 42% very helpful, 34% somewhat helpful
- Muscle/joint pain: 28% very helpful, 44% somewhat helpful
- Bone, joint, and soft tissue issues: 26% very helpful, 44% somewhat helpful
- Neuropathy: 27% very helpful, 41% somewhat helpful
- Anxiety: 25% very helpful, 40% somewhat helpful
- Depression: 24% very helpful, 41% somewhat helpful
- Feeling overly tired: 24% very helpful, 39% somewhat helpful
- Memory loss, cognitive issues: 14% very helpful, 30% somewhat helpful

61% of Immunotherapy patients say providers were “very helpful” in addressing dermatological problems

“I wish I'd understood that post-treatment would have had such an impact on me mentally. I don't know that my oncology team has the means to truly screen for that either.”

- Completed Treatment
Providers are more helpful with nausea and vomiting, but less helpful with key side effects like fatigue, anxiety, and depression.
I wish I had known....

- Patients say they wish they had known more about the severity of side effects and long term management; mental health side effects; and fertility/sexual health side effects.

More information about immunotherapy and the possible side effects.
- Immunotherapy patient, In Tx Recurrence

I wish I had known about fertility preservation.
- Metastatic Cancer patient

How living with the fear of recurrence or metastasis can be exhausting, but CAN be managed, through diet, exercise and support groups.
- In Treatment for Initial Diagnosis

I wish the oncologist would have told me it was 'normal' to experience pain, fatigue, and depression with cancer.
- Completed Tx

Long term survivorship issues such as loss of libido and its effect on marriage, how to handle lasting aches and pains, value of exercise to mental health.
- Completed Treatment

The mental side of things would be worse after treatment is finished.
- Immunotherapy patient, Completed Tx
Post-Treatment Information and Care
Few feel “very” prepared or informed about transition to post-treatment

- More vulnerable patient populations (low income, in poor health) are significantly less likely to feel prepared and informed.

**Prepared for transition from active to post-treatment**

- **Very**: 15%
- **Somewhat**: 51%
- **Not**: 30%
- **Not sure**: 4%

**Informed about how to manage your health post-treatment**

- **Very**: 26%
- **Somewhat**: 52%
- **Not**: 19%
- **Not sure**: 2%

More likely NOT prepared:
- Income <$50k: 37%
- Fair/Poor health: 37%

More likely NOT informed:
- Fair/poor health: 25%
Half initiate conversations with their healthcare team about post-treatment

- Who is responsible for post-treatment care is the topic most discussed. Few discuss financial services/support, survivorship plans, or emotional support.

84% have spoken with doctor/HCP about post-treatment

- Yes, I asked doc/HCP, 54%
- Yes, doc/HCP brought it up, 30%
- No, 16%

Which of the following did you discuss/receive from your doctor/HCP about transition to post-treatment? (select all)

- What HCP should manage post-tx: 42%
- Long-term side effects: 39%
- Exercise and nutrition: 38%
- What to expect in post-tx phase: 38%
- Emotional/psychological services/support: 31%
- Survivorship care plan or next step summary: 30%
- Financial services/support: 13%
- None of the above: 11%

More likely provider-initiated:
- Immunotherapy: 44%
- In Tx (Recur): 42%
- Stage 2: 42%

More likely discussed:
- Immunotherapy: 21%
- In Tx (Recur): 22%
- Medicaid: 23%
Expectation of *who* will manage post-treatment care

- Oncologists are most likely to head up the post-treatment care for all audiences

### Who will manage your post-tx care?

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Comp Tx</th>
<th>In Tx (Rec)</th>
<th>Metastatic</th>
<th>Immunotherapy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Oncologist</strong></td>
<td>44%</td>
<td>42%</td>
<td>48%</td>
<td>52%</td>
<td>53%</td>
</tr>
<tr>
<td><strong>Primary care provider</strong></td>
<td>39%</td>
<td>40%</td>
<td>38%</td>
<td>33%</td>
<td>42%</td>
</tr>
<tr>
<td><strong>Other specialist</strong></td>
<td>10%</td>
<td>11%</td>
<td>5%</td>
<td>10%</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Not sure/Don’t know</strong></td>
<td>8%</td>
<td>8%</td>
<td>9%</td>
<td>5%</td>
<td>3%</td>
</tr>
</tbody>
</table>

Top *Other* mentions:
- Dermatologist
- Endocrinologist
- Gynecologist
- Surgeon
Doctor’s office is the most common setting for post-treatment care

- This setting is far less common during treatment.
- Patients are also less likely to receive post-treatment care from hospitals and medical centers, where most received treatment for their cancer.
Patients are mixed on the quality of their post-treatment care

- Just a quarter describe it as “excellent,” and in open-ended questions, many voice concerns about getting enough attention and preparation from their providers.

**How would you evaluate your post-tx care?**

- Excellent, 28%
- Good, 38%
- Fair, 20%
- Poor, 8%

*Satisfaction levels were consistent across audiences*

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**In their own words...**

- *I think there are "survivorship" issues that should really be discussed as part of treatment, not just when treatment ends.*
  - Completed Tx

- *Once I was out of active treatment, I was no longer be considered a priority to my oncology team.*
  - Immunotherapy patient, Completed Tx

- *Survivorship was harder than treatments.*
  - Immunotherapy patient, Completed Tx

- *I wish that my healthcare team would address survivorship issues and long term effects of my cancer diagnosis. At this point I am just told to call if there are any changes in the way that I feel, this leaves me feeling uneasy and uncertain about the future of my health.*
  - Immunotherapy patient, In tx reoccurrence
As a result, some rely on online sources for information vs. doctors

- Sources of post-treatment information were consistent across audiences.

<table>
<thead>
<tr>
<th>Sources of information about post-treatment care &amp; support</th>
<th>Completed Tx</th>
<th>In Tx (Recur)</th>
<th>Metastatic</th>
<th>Immuno-therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online sources</td>
<td>55%</td>
<td>61%</td>
<td>62%</td>
<td>45%</td>
</tr>
<tr>
<td>Oncologist</td>
<td>45%</td>
<td>48%</td>
<td>43%</td>
<td>41%</td>
</tr>
<tr>
<td>Support groups/other patients</td>
<td>39%</td>
<td>43%</td>
<td>37%</td>
<td>28%</td>
</tr>
<tr>
<td>Patient advocacy organizations</td>
<td>32%</td>
<td>35%</td>
<td>34%</td>
<td>23%</td>
</tr>
<tr>
<td>Print sources</td>
<td>29%</td>
<td>31%</td>
<td>29%</td>
<td>17%</td>
</tr>
<tr>
<td>Primary care doctor</td>
<td>28%</td>
<td>28%</td>
<td>29%</td>
<td>35%</td>
</tr>
<tr>
<td>Nurse/Nurse practitioner</td>
<td>24%</td>
<td>22%</td>
<td>30%</td>
<td>32%</td>
</tr>
<tr>
<td>Friends/family</td>
<td>22%</td>
<td>22%</td>
<td>23%</td>
<td>23%</td>
</tr>
<tr>
<td>Social worker/psychologist</td>
<td>14%</td>
<td>14%</td>
<td>14%</td>
<td>17%</td>
</tr>
<tr>
<td>Other specialist</td>
<td>5%</td>
<td>6%</td>
<td>7%</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>5%</td>
<td>6%</td>
<td>3%</td>
</tr>
<tr>
<td>None of the above</td>
<td>3%</td>
<td>2%</td>
<td>4%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Patients 65+ more likely to rely on: Print (42%), PCP (35%) and specialists (12%)
Survivorship Needs
Having cancer at any age is hard. But at the height of your career, us middle aged people who are outliers for cancer and not eligible for Medicare are just trying to figure out how to maintain income and health insurance.

“More understanding about managing long term side effects and/or new ones that arise from previous treatment would be helpful.”

“I do wish that my healthcare team did more to address the emotional side effects, particularly in screening for it. I developed a lot of anxiety, but I just thought it was normal. Only in retrospect did I realize I had a problem.”

“Having cancer at any age is hard. But at the height of your career, us middle aged people who are outliers for cancer and not eligible for Medicare are just trying to figure out how to maintain income and health insurance.”
Top concerns are a mix of financial, physical, and emotional

- More vulnerable patient populations have higher levels of concern.

<table>
<thead>
<tr>
<th>Top 5 “Major Concerns”</th>
<th>%Total</th>
<th>Most concerned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting/keeping health insurance</td>
<td>45%</td>
<td>Medicaid = 61% Income &lt;$50k = 57%</td>
</tr>
<tr>
<td>Having the financial support you need</td>
<td>42%</td>
<td>Income &lt;$50k = 64% Medicaid = 55% Fair/poor health= 51%</td>
</tr>
<tr>
<td>Managing on-going side effects from treatment</td>
<td>42%</td>
<td>Age 18-39 = 51% Income &lt;$50k = 54% Medicaid = 53% Fair/poor health= 50%</td>
</tr>
<tr>
<td>Uncertainty about the future</td>
<td>41%</td>
<td>Medicaid = 53% Fair/poor health= 50%</td>
</tr>
<tr>
<td>Having the energy to make it through the day</td>
<td>39%</td>
<td>Medicaid = 59% Income &lt;$50k = 51% Fair/poor health= 51% Age 18-39 = 48%</td>
</tr>
</tbody>
</table>
Patients in treatment for their initial diagnosis have highest concerns across issues

<table>
<thead>
<tr>
<th>Major concern</th>
<th>Total</th>
<th>Completed Tx</th>
<th>In Tx (Initial)</th>
<th>In Tx (Recur)</th>
<th>Meta-static</th>
<th>Immuno-therapy</th>
</tr>
</thead>
<tbody>
<tr>
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<td>48%</td>
</tr>
<tr>
<td>Having the financial support you need</td>
<td>42%</td>
<td>37%</td>
<td>54%</td>
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<td>Managing on-going side effects from treatment</td>
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<td>Uncertainty about the future</td>
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<td>40%</td>
</tr>
<tr>
<td>Having the energy to make it through the day</td>
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<td>40%</td>
<td>37%</td>
<td>43%</td>
</tr>
<tr>
<td>Maintaining a healthy weight</td>
<td>39%</td>
<td>41%</td>
<td>41%</td>
<td>32%</td>
<td>31%</td>
<td>36%</td>
</tr>
<tr>
<td>Afford prescribed medications/treatments</td>
<td>38%</td>
<td>34%</td>
<td>48%</td>
<td>34%</td>
<td>40%</td>
<td>40%</td>
</tr>
<tr>
<td>Being there for your family and friends</td>
<td>36%</td>
<td><strong>29%</strong></td>
<td>49%</td>
<td>35%</td>
<td>42%</td>
<td>40%</td>
</tr>
<tr>
<td>Getting enough exercise</td>
<td>35%</td>
<td>36%</td>
<td>33%</td>
<td>38%</td>
<td>30%</td>
<td>39%</td>
</tr>
<tr>
<td>Dealing with mental health issues</td>
<td>34%</td>
<td>31%</td>
<td><strong>44%</strong></td>
<td>30%</td>
<td>31%</td>
<td>39%</td>
</tr>
<tr>
<td>Understanding health insurance benefits available</td>
<td>33%</td>
<td><strong>27%</strong></td>
<td>42%</td>
<td>36%</td>
<td>33%</td>
<td>36%</td>
</tr>
<tr>
<td>Maintaining a proper diet</td>
<td>33%</td>
<td>32%</td>
<td>35%</td>
<td>33%</td>
<td>31%</td>
<td>38%</td>
</tr>
<tr>
<td>Long-term planning/career goals</td>
<td>33%</td>
<td><strong>28%</strong></td>
<td>40%</td>
<td>37%</td>
<td>32%</td>
<td>40%</td>
</tr>
<tr>
<td>Having the emotional support you need</td>
<td>32%</td>
<td>27%</td>
<td>44%</td>
<td>29%</td>
<td>30%</td>
<td>29%</td>
</tr>
<tr>
<td>Work/employment issues</td>
<td>31%</td>
<td>27%</td>
<td>36%</td>
<td>33%</td>
<td>27%</td>
<td>35%</td>
</tr>
<tr>
<td>Life transitions</td>
<td>31%</td>
<td><strong>24%</strong></td>
<td>41%</td>
<td>32%</td>
<td>29%</td>
<td>35%</td>
</tr>
<tr>
<td>Ability to find/maintain a relationship with a significant other</td>
<td>30%</td>
<td>24%</td>
<td>41%</td>
<td>29%</td>
<td>22%</td>
<td>32%</td>
</tr>
<tr>
<td>Maintaining relationships with family and friends</td>
<td>28%</td>
<td><strong>21%</strong></td>
<td>43%</td>
<td>29%</td>
<td><strong>22%</strong></td>
<td>36%</td>
</tr>
<tr>
<td>Visiting your doctor regularly</td>
<td>28%</td>
<td>20%</td>
<td>44%</td>
<td>24%</td>
<td>19%</td>
<td>41%</td>
</tr>
<tr>
<td>Managing prescribed medications/treatments</td>
<td>26%</td>
<td><strong>17%</strong></td>
<td>41%</td>
<td>27%</td>
<td>17%</td>
<td>37%</td>
</tr>
<tr>
<td>Completing insurance paperwork</td>
<td>26%</td>
<td><strong>17%</strong></td>
<td>39%</td>
<td>29%</td>
<td><strong>16%</strong></td>
<td>35%</td>
</tr>
<tr>
<td>Traveling</td>
<td>20%</td>
<td><strong>14%</strong></td>
<td>24%</td>
<td>31%</td>
<td>25%</td>
<td>30%</td>
</tr>
<tr>
<td>Starting a family/having children</td>
<td>15%</td>
<td><strong>11%</strong></td>
<td>20%</td>
<td>17%</td>
<td><strong>11%</strong></td>
<td>25%</td>
</tr>
</tbody>
</table>
In most cases, a third or less rate their healthcare team as “very helpful” on the range of issues tested.

<table>
<thead>
<tr>
<th>HC Team Very Helpful</th>
<th>Total</th>
<th>Completed Tx</th>
<th>In Tx (Initial)</th>
<th>In Tx (Recur)</th>
<th>Meta-static</th>
<th>Immuno-therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visiting your doctor regularly</td>
<td>41%</td>
<td>39%</td>
<td>47%</td>
<td>36%</td>
<td>46%</td>
<td>39%</td>
</tr>
<tr>
<td>Managing prescribed medications/treatments</td>
<td>34%</td>
<td>27%</td>
<td>44%</td>
<td>35%</td>
<td>39%</td>
<td>40%</td>
</tr>
<tr>
<td>Managing on-going side effects from treatment</td>
<td>27%</td>
<td>23%</td>
<td>32%</td>
<td>31%</td>
<td>36%</td>
<td>36%</td>
</tr>
<tr>
<td>Completing insurance paperwork</td>
<td>27%</td>
<td>20%</td>
<td>34%</td>
<td>34%</td>
<td>33%</td>
<td>39%</td>
</tr>
<tr>
<td>Having the emotional support you need</td>
<td>23%</td>
<td>17%</td>
<td>32%</td>
<td>28%</td>
<td>21%</td>
<td>37%</td>
</tr>
<tr>
<td>Dealing with mental health issues</td>
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<td>17%</td>
<td>29%</td>
<td>25%</td>
<td>23%</td>
<td>36%</td>
</tr>
<tr>
<td>Affording prescribed medications/treatments</td>
<td>22%</td>
<td>15%</td>
<td>35%</td>
<td>23%</td>
<td>21%</td>
<td>31%</td>
</tr>
<tr>
<td>Understanding health insurance benefits available</td>
<td>21%</td>
<td>15%</td>
<td>31%</td>
<td>24%</td>
<td>22%</td>
<td>36%</td>
</tr>
<tr>
<td>Maintaining a proper diet</td>
<td>20%</td>
<td>16%</td>
<td>28%</td>
<td>21%</td>
<td>23%</td>
<td>33%</td>
</tr>
<tr>
<td>Getting enough exercise</td>
<td>19%</td>
<td>15%</td>
<td>23%</td>
<td>25%</td>
<td>16%</td>
<td>30%</td>
</tr>
<tr>
<td>Having the energy to make it through the day</td>
<td>19%</td>
<td>14%</td>
<td>26%</td>
<td>24%</td>
<td>19%</td>
<td>31%</td>
</tr>
<tr>
<td>Maintaining a healthy weight</td>
<td>19%</td>
<td>14%</td>
<td>26%</td>
<td>18%</td>
<td>22%</td>
<td>28%</td>
</tr>
<tr>
<td>Getting/keeping health insurance</td>
<td>18%</td>
<td>12%</td>
<td>26%</td>
<td>21%</td>
<td>17%</td>
<td>30%</td>
</tr>
<tr>
<td>Being there for your family and friends</td>
<td>17%</td>
<td>12%</td>
<td>24%</td>
<td>21%</td>
<td>12%</td>
<td>32%</td>
</tr>
<tr>
<td>Life transitions</td>
<td>16%</td>
<td>11%</td>
<td>25%</td>
<td>20%</td>
<td>13%</td>
<td>29%</td>
</tr>
<tr>
<td>Uncertainty about the future</td>
<td>16%</td>
<td>12%</td>
<td>22%</td>
<td>17%</td>
<td>14%</td>
<td>24%</td>
</tr>
<tr>
<td>Traveling</td>
<td>16%</td>
<td>11%</td>
<td>21%</td>
<td>22%</td>
<td>14%</td>
<td>29%</td>
</tr>
<tr>
<td>Maintaining relationships with family and friends</td>
<td>15%</td>
<td>10%</td>
<td>22%</td>
<td>21%</td>
<td>13%</td>
<td>26%</td>
</tr>
<tr>
<td>Having the financial support you need</td>
<td>15%</td>
<td>10%</td>
<td>21%</td>
<td>24%</td>
<td>11%</td>
<td>32%</td>
</tr>
<tr>
<td>Relationship with a significant other</td>
<td>15%</td>
<td>10%</td>
<td>22%</td>
<td>17%</td>
<td>9%</td>
<td>27%</td>
</tr>
<tr>
<td>Long-term planning/career goals</td>
<td>13%</td>
<td>9%</td>
<td>15%</td>
<td>18%</td>
<td>9%</td>
<td>26%</td>
</tr>
<tr>
<td>Work/employment issues</td>
<td>12%</td>
<td>7%</td>
<td>17%</td>
<td>20%</td>
<td>11%</td>
<td>25%</td>
</tr>
<tr>
<td>Starting a family/having children</td>
<td>10%</td>
<td>6%</td>
<td>15%</td>
<td>15%</td>
<td>2%</td>
<td>21%</td>
</tr>
</tbody>
</table>
There is a disconnect between patient concerns and support from HCPs

- Healthcare teams are most helpful with adherence issues, but less helpful with the insurance/financial and emotional concerns that top the list for patients.

**Mapping HCP Helpfulness on Patients Top Concerns**

- Average V. Concerned: 33%
- Average V. Helpful: 20%

- **Physical Health/Adherence**:
  - Dealing with mental health issues (e.g., anxiety or depression)
  - Getting enough exercise
  - Getting/keeping health insurance
  - Managing on-going side effects from treatment

- **Financial/Insurance**:
  - Having the energy to make it through the day
  - Maintaining a healthy weight
  - Getting the financial support you need

- **Emotional/Lifestyle**:
  - Uncertainty about the future
  - Being there for your family and friends
  - Having the financial support you need

- Physical Health/Adherence - Orange
- Financial/Insurance - Green
- Emotional/Lifestyle - Blue
Survivorship resources are of interest, but not widely available through HCPs

Which resources are available through your HC team and would you use?

- Nutrition Programs: 48% available, 51% want
- Mental health support groups: 39% available, 43% want
- Long term symptom management programs: 31% available, 52% want
- Exercise classes: 26% available, 44% want
- Alternative medicine programs: 25% available, 44% want
- Insurance coverage education: 19% available, 33% want
- Return to work information: 14% available, 16% want
- None of the above: 25% available, 12% want

Currently available through HCP
Do/would use if available through HCP
In their own words...

- When asked what resources or services they are NOT receiving that would be most helpful, most talk about emotional and financial support.
- Many want to know where to go for help, beyond HCPs.

“I am not critical of my healthcare providers for not helping with these services. I honestly don’t expect them to—they need to concentrate on medicine. But, I honestly don’t know where to go for help with these issues.” -In Tx (Recurrence)

“Being assigned a case worker to help with insurance benefits. Being assigned someone who can help find resources for my emotional support. I feel like I don’t really know what is next. Feel a bit rushed in certain cases to get out of the office and move on. Then I try to live a normal life, but I don’t know what that looks like.” -In Tx (Initial)

“I would like to meet more cancer survivors. I feel now that I am a different person and that no one understands what I’ve been through. Most people think that because you survived, that you are great and not in need any more. It would be helpful to have some friends who have gone through the same journey.” -Metastatic patient (completed tx)

“Mental health counselling for anxiety about the future. Also navigating individual health insurance needs.” -Immunotherapy, In Tx (Initial)
Wrap-up: Key Areas of Need

- There are many ways that NCCS and its partners can impact the survivorship needs of diverse groups of cancer patients.

1. Mental health side effects (depression and anxiety) are common and last well beyond treatment, yet are not well addressed by healthcare providers. Patients say emotional support is a big area of need post-treatment – from mental health counseling to support groups.

2. While many are discussing post-treatment with their healthcare providers, these conversations are mostly logistical (i.e. who will manage post-treatment care). As a result, many rely on online sources for information and support, and indicate they need more resources.

3. Insurance coverage, financial support, and long term symptom management are top patient concerns. There is also high interest in access to resources/programs for these issues through HCPs. However, few HCPs are currently providing them and many patients wonder where they can go to get these supports.

4. Younger patients (18-39) and more vulnerable populations (low income, Medicaid, in poor health) have higher levels of concern across a range of issues. More vulnerable populations are also less likely to say their HCPs have been helpful with these issues.

5. Immunotherapy patients are more satisfied with their post treatment experiences. They are significantly more likely to report feeling prepared and informed, and while they share many concerns around financial and emotional issues, they also report higher levels of help from HCPs in dealing with these challenges.
Immunotherapy patients have different, better post-treatment experiences

- Survey findings point to a few differences in post-treatment experiences & concerns:

  **Most report fewer side effects:**
  - Less likely to experience multiple side effects. Rates of those reported are in keeping with other audiences.
  - Dermatological issues are within their top 3 most severe side effects, but they are also significantly more likely than other groups to say HCPs have been “very helpful” in addressing these.

  **Survivorship concerns** are similar to others’ but they receive greater support from their providers
  - More likely to have major concerns around visiting a doctor regularly (41% vs. 28% total) and starting a family/having children (25% v. 15%)
  - Similar levels of concern as other audiences about financial and emotional issues/challenges. However, significantly more likely to say HCPs have been “very helpful” in addressing financial and emotional concerns

**Most have undergone multiple treatments:**
- Most are currently in treatment (38% recurrence, 40% initial diagnosis) and have undergone multiple treatments (chemo 74%, surgery 73%, targeted drug therapy 70%, radiation 68%)

**Are better prepared and informed for post-treatment than other audiences**
- More likely than other audiences to feel prepared, informed about post-treatment transition and more likely to say their HCP initiated these conversations.

**Demographically, those surveyed were younger and higher income:**
- 31% age 18-39 v. 20% total
- 66% income >$75k (v. 47% total)

- It is important to note that the term “immunotherapy” is still not widely understood by the community. Over a quarter (28%) of respondents who indicated they had received immunotherapy (after reading a definition) had a cancer diagnosis for which no immunotherapy products with FDA-approved indications were available at the time of the survey.
Appendix A: Profile of Cancer Survivors
Demographics

- The sample is a good distribution of age and region.
- Respondents skew female and are more Caucasian than the U.S. population.
Demographics

- Respondents skew higher SES than the U.S. population, though there is a mix of education and income.
- While most are privately insured, nearly 1-in-10 are Medicaid patients.
- Two-thirds of respondents are married.

**EDUCATION**
- < than college: 8%
- Some College/2-yr degree/ Vocational: 33%
- Bachelor’s degree: 28%
- Postgraduate work/degree: 30%

**INCOME**
- <$25K: 8%
- $25-50K: 14%
- $50-75K: 17%
- $75-100K: 22%
- $100K+: 30%

**INSURANCE**
- 24% Medicare
- 9% Medicaid
- 43% Private/employer
- 16% Private/spouse or parents

**MARITAL STATUS**
- Married: 64%
- Single: 12%
- Divorced: 12%
- Other: 12%
Health Profile

- Respondents represent a range of cancer stages and types; a third are breast cancer survivors.
- Current health status varies greatly – few describe themselves as in “excellent” health.

**STATE OF PHYSICAL HEALTH**
- Excellent, 7%
- Good, 44%
- Fair, 33%
- Poor, 12%

**STATE OF EMOTIONAL HEALTH**
- Excellent, 11%
- Good, 37%
- Fair, 37%
- Poor, 14%

**TYPE OF CANCER (TOP 5)**
- Breast: 31%
- Colon/Rectal: 16%
- Melanoma: 10%
- Gynecological: 9%
- Lymphoma: 7%

**CANCER STAGE**
- I: 22%
- II: 31%
- III: 22%
- IV: 12%

**AGE AT DIAGNOSIS**
- 18-39: 31%
- 40-49: 36%
- 50-64: 29%
- 65+: 4%
Treatment Profile

- Half of respondents have completed treatment, with a range in time since the last treatment (from within 6 months to more than 10 years).
- The majority have undergone surgery, chemotherapy, and/or radiation.

**TREATMENT STATUS**

- I am currently receiving treatment for my initial cancer diagnosis: 28%
- I am currently receiving treatment for cancer that has recurred: 19%
- I have completed treatment and/or am not currently in active treatment for cancer: 50%

**TYPES OF TREATMENT(S)**

- Surgery: 81%
- Chemotherapy: 77%
- Radiation therapy: 58%
- Targeted drug therapy: 48%
- Other: 32%
- Immuno-Therapy: 27%

**YEARS POST-TREATMENT**

- Still undergoing treatment: 30%
- Less than 6 months ago: 13%
- 6 months to less a year: 12%
- 1-5 years: 27%
- 6-10 years: 9%
- More than 10 years ago: 10%

**LOCATION OF TREATMENT**

- Academic Medical Center: 34%
- Community Hospital: 31%
- Community Cancer Center: 25%
- Doctor’s Office: 16%
- Private Cancer Center: 13%
# Audiences Profiles and Differences

## Completed Treatment (50%)
- More likely to be breast cancer (35%) patients
- More likely to report excellent/good physical health (65%) as well as excellent emotional health (14%)
- More likely to have had stage 1 cancer (26%)
- Higher rates of surgery (88%)
- Demographics:
  - Most are over age 50 (62%)
  - Highly educated (39% with postgraduate work/degree)

## In Treatment for Initial Diagnosis (28%)
- More likely to be patients with myeloma (4%), lung cancer (10%) and breast cancer (31%)
- Most likely to report being in poor emotional health (24%)
- More likely to have stage 1 cancer (24%)

## In Treatment for Recurrence (19%)
- Most are colon/rectal (24%), breast (18%) or melanoma (18%) patients
- High treatment rates overall
  - 86% surgery, 86% chemo, 71% radiation, 54% immunotherapy
- Lower education levels compared to other audiences (27% some college)

---

**Blue (higher) / Red (lower)** indicates statistical significance across at least 3 key audiences
# Audience Profiles and Differences

<table>
<thead>
<tr>
<th>Metastatic Cancer Patients (12%)</th>
<th>Immunotherapy Patients (27%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Most are over age 50 (63%)</td>
<td>• Significantly younger than other audiences (31% age 18-39)</td>
</tr>
<tr>
<td>• More likely to be colon/rectal cancer (31%) and lymphoma (14%) patients</td>
<td>• High SES: Most likely to be college graduates (43%); 68% income &gt;$75k</td>
</tr>
<tr>
<td>• More likely to have been diagnosed at older age (43% diagnosed age 50+)</td>
<td>• Most are melanoma (29%) or colon/rectal (22%) patients; many are stage 2 (42%)</td>
</tr>
<tr>
<td>• 45% have completed their treatment; 36% are in treatment for initial diagnosis</td>
<td>• Over a third diagnosed at younger age (37% diagnosed age 18-39)</td>
</tr>
<tr>
<td>• Most likely to have received chemo (89%), lower rates of other treatments</td>
<td>• Most are currently in treatment (38% recurrence, 40% initial diagnosis)</td>
</tr>
<tr>
<td></td>
<td>• Most have undergone other treatments (chemo 74%, surgery 73%, targeted drug therapy 70%, radiation 68%)</td>
</tr>
<tr>
<td></td>
<td>• Most likely to have received treatment at private cancer center (19%)</td>
</tr>
</tbody>
</table>

**Blue (higher) / Red (lower) indicates statistical significance across at least 3 key audiences**
Appendix B: Drill Down on Patient Needs
Drill Down: Financial/Insurance

- Low income, Medicaid, and in some instances younger patients, struggle more with financial and insurance issues.

<table>
<thead>
<tr>
<th>Major Concerns</th>
<th>Age 18-39</th>
<th>Age 40-64</th>
<th>Age 65+</th>
<th>Income &lt;$50K</th>
<th>Income $50K-$100K</th>
<th>Income &gt;$100K</th>
<th>Insurance Private</th>
<th>Insurance Medicare</th>
<th>Insurance Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting/keeping health insurance</td>
<td>50%</td>
<td>49%</td>
<td>20%</td>
<td>57%</td>
<td>42%</td>
<td>39%</td>
<td>44%</td>
<td>37%</td>
<td>61%</td>
</tr>
<tr>
<td>Having the financial support you need</td>
<td>46%</td>
<td>45%</td>
<td>24%</td>
<td>64%</td>
<td>41%</td>
<td>31%</td>
<td>41%</td>
<td>37%</td>
<td>55%</td>
</tr>
<tr>
<td>Being able to afford your prescribed medications and other treatments</td>
<td>44%</td>
<td>39%</td>
<td>23%</td>
<td>56%</td>
<td>39%</td>
<td>25%</td>
<td>37%</td>
<td>34%</td>
<td>43%</td>
</tr>
<tr>
<td>Understanding the health insurance benefits available to you</td>
<td>42%</td>
<td>34%</td>
<td>13%</td>
<td>43%</td>
<td>35%</td>
<td>25%</td>
<td>32%</td>
<td>28%</td>
<td>50%</td>
</tr>
<tr>
<td>Completing insurance paperwork</td>
<td>34%</td>
<td>26%</td>
<td>10%</td>
<td>34%</td>
<td>28%</td>
<td>20%</td>
<td>25%</td>
<td>23%</td>
<td>43%</td>
</tr>
</tbody>
</table>

Note: Statistical differences shown are within categories
Helpfulness of HCPs: Financial/Insurance

- Younger patients, those with higher income levels, and those on immunotherapy are more likely to say their HCPs were “very helpful” with these issues.

Helpfulness of health care team in helping/monitoring these issues

- Getting/keeping health insurance
- Having the financial support you need
- Being able to afford your prescribed medications and other treatments
- Understanding the health insurance benefits available to you
- Completing insurance paperwork

More likely “very helpful”:
- Immunotherapy patients
- Patients age 18-39
- Higher income (above $50k)
- College & below education

Note: Issues ranked in order of concern
Helpfulness of HCPs: Financial/Insurance

- HCPs are most helpful with understanding benefits and completing paperwork, less helpful with financial support.
Drill Down: Physical Health & Adherence

- Younger patients and those in fair/poor health are most likely to have concerns around health effects and adherence.

<table>
<thead>
<tr>
<th>Major Concerns</th>
<th>Age</th>
<th>Income</th>
<th>Health Status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>18-39</td>
<td>40-64</td>
<td>65+</td>
</tr>
<tr>
<td>Managing on-going side effects from treatment</td>
<td>42%</td>
<td></td>
<td>51% 43% 29%</td>
</tr>
<tr>
<td>Having the energy to make it through the day</td>
<td>39%</td>
<td></td>
<td>48% 39% 25%</td>
</tr>
<tr>
<td>Maintaining a healthy weight</td>
<td>39%</td>
<td></td>
<td>40% 40% 31%</td>
</tr>
<tr>
<td>Getting enough exercise</td>
<td>35%</td>
<td></td>
<td>42% 34% 31%</td>
</tr>
<tr>
<td>Maintaining a proper diet</td>
<td>33%</td>
<td></td>
<td>38% 32% 25%</td>
</tr>
<tr>
<td>Visiting your doctor regularly</td>
<td>28%</td>
<td></td>
<td>40% 26% 16%</td>
</tr>
<tr>
<td>Managing all of your prescribed medications/treatments</td>
<td>26%</td>
<td></td>
<td>34% 25% 15%</td>
</tr>
</tbody>
</table>

Note: Statistical differences shown are within categories
Helpfulness of HCPs: Physical/Health

- Younger patients and immunotherapy patients are more likely to say their healthcare team has been “very helpful” in monitoring health and adherence issues.

Helpfulness of health care team in helping/monitoring these issues

- **Managing ongoing side effects from treatment**: 72%
  - Very helpful: 45%
  - Somewhat helpful: 27%
- **Having the energy to make it through the day**: 56%
  - Very helpful: 37%
  - Somewhat helpful: 19%
- **Maintaining a healthy weight**: 61%
  - Very helpful: 42%
  - Somewhat helpful: 19%
- **Getting enough exercise**: 58%
  - Very helpful: 39%
  - Somewhat helpful: 19%
- **Maintaining a proper diet**: 62%
  - Very helpful: 42%
  - Somewhat helpful: 20%
- **Visiting your doctor regularly**: 80%
  - Very helpful: 41%
  - Somewhat helpful: 39%
- **Managing all of your prescribed medications/treatments**: 71%
  - Very helpful: 37%
  - Somewhat helpful: 34%

More likely “very helpful”:
- Immunotherapy patients
- Patients age 18-39
- Beyond college Ed

Note: Issues ranked in order of concern
Helpfulness of HCPs: Health/Adherence

- HCPs are most helpful in ensuring regular doctor visits and managing medications.

![Graph showing the percentage of patients who find different health activities helpful and major concerns.](image-url)
**Drill Down: Emotional/Lifestyle**

- Younger patients and those who classify themselves as in poor emotional health are significantly more likely to have concerns for all issues listed.

<table>
<thead>
<tr>
<th>Major Concerns</th>
<th>Age</th>
<th>Income</th>
<th>Emotional Health Status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>18-39</td>
<td>40-64</td>
<td>65+</td>
</tr>
<tr>
<td>Uncertainty about the future</td>
<td>41%</td>
<td>46%</td>
<td>44%</td>
</tr>
<tr>
<td>Being there for your family and friends</td>
<td>36%</td>
<td>44%</td>
<td>37%</td>
</tr>
<tr>
<td>Dealing with mental health issues</td>
<td>34%</td>
<td>48%</td>
<td>34%</td>
</tr>
<tr>
<td>Long-term planning/career goals</td>
<td>33%</td>
<td>43%</td>
<td>34%</td>
</tr>
<tr>
<td>Having the emotional support you need</td>
<td>32%</td>
<td>43%</td>
<td>32%</td>
</tr>
<tr>
<td>Work/employment issues, like finding and keeping a job</td>
<td>31%</td>
<td>40%</td>
<td>32%</td>
</tr>
<tr>
<td>Life transitions</td>
<td>31%</td>
<td>42%</td>
<td>31%</td>
</tr>
<tr>
<td>Ability to find/maintain a relationship with a S.O.</td>
<td>30%</td>
<td>39%</td>
<td>30%</td>
</tr>
<tr>
<td>Ability to maintain relationships w/ family &amp; friends</td>
<td>28%</td>
<td>37%</td>
<td>29%</td>
</tr>
<tr>
<td>Traveling</td>
<td>20%</td>
<td>27%</td>
<td>19%</td>
</tr>
<tr>
<td>Starting a family/having children</td>
<td>15%</td>
<td>36%</td>
<td>11%</td>
</tr>
</tbody>
</table>

Note: Statistical differences shown are within categories.
Helpfulness of HCPs: Emotional/Lifestyle

- Younger patients and immunotherapy patients are more likely to say their healthcare team has been “very helpful” in monitoring health and adherence issues.

**Helpfulness of health care team in helping/monitoring these issues**

- Uncertainty about the future: 54% very helpful, 38% somewhat helpful
- Being there for family and friends: 46% very helpful, 29% somewhat helpful
- Dealing with mental health issues: 62% very helpful, 22% somewhat helpful
- Long-term planning/career goals: 36% very helpful, 23% somewhat helpful
- Emotional support: 58% very helpful, 35% somewhat helpful
- Work/employment issues: 46% very helpful, 33% somewhat helpful
- Life transitions: 62% very helpful, 21% somewhat helpful
- Relationship with a S.O.: 41% very helpful, 26% somewhat helpful
- Relationship w/family & friends: 41% very helpful, 25% somewhat helpful
- Traveling: 41% very helpful, 28% somewhat helpful
- Starting a family/having children: 41% very helpful, 18% somewhat helpful

**More likely “very helpful”:**
- Immunotherapy patients
- Patients age 18-39
- Higher income (above $50k)
- College & below Ed

*Note: Issues ranked in order of concern*
Helpfulness of HCPs: Emotional/Lifestyle

- HCPs are slightly more helpful with emotional support and mental health concerns, but far less helpful with relationship and career/work related issues.