TABLE OF CONTENTS

Context and Objectives 4
Research Methods 6
Strategic Conclusions 8
Detailed Analysis of Results 15
Patients 16
Caregivers 40
Appendix 65
The objective of this study is to investigate the experiences of both cancer patients and their caregivers with regards to access to coverage, treatment, information, and supplemental support.

The survey will determine:

- How patients and caregivers navigate both the public and private benefits systems;
- How decisions around care are made, including sources of information and their influence;
- Interest in out-of-hospital care, from home care to alternative health treatments to private clinics to patient support groups;
- The already-established relationship between patients/caregivers and pharmaceutical companies, including awareness and reputation.
RESEARCH METHODS
INSTRUMENT
A survey of 502 Canadians who have cancer, have had cancer in the past, are currently caregivers to someone with cancer, OR have been a caregiver in the past was completed online between May 9 to May 18, 2013 using Leger Marketing’s online panel, LegerWeb.

A probability sample of the same size would yield a margin of error of +/- 4.4%, 19 times out of 20.

ONLINE PANEL
Leger Marketing’s online panel has approximately 460,000 members nationally – with between 10,000 and 20,000 new members added each month, and has a retention rate of 90%.

Panel members are randomly selected to receive email invitations to the individual surveys.

We ensure the protection of privacy via the usage of unique URLs and respondent IDs in combination with survey IDs.

QUALITY CONTROL
Stringent quality assurance measures allow Leger Marketing to achieve the high-quality standards set by the company. As a result, its methods of data collection and storage outperform the norms set by WAPOR (The World Association for Public Opinion Research). These measures are applied at every stage of the project: from data collection to processing, through to analysis. We aim to answer our clients’ needs with honesty, total confidentiality, and integrity.
Significant differences emerged between the patient sample and the caregiver sample. We have identified some possible explanations:

- Understandably, the patient sample was composed of those survived their battle with cancer; we were unable to survey those who did not, and so their experiences were not recorded. Those who survived may be likely to look back on their experiences more positively, and gloss over frustrations or struggles.

- The caregiver sample captures individuals who cared for cancer patients who passed away, as well as those who survived or are currently struggling. Those patients may have had more rare or complex forms of the disease, which resulted in a different, potentially more frustrating healthcare experience.

- Caregivers are more likely than patients to be on the frontlines of acquiring and managing treatment and care – they may have a more in-depth experience with both public and private coverage, and may even have shielded their dependents from the worst of it, contributing to the difference in perceptions this survey captured.
Patients and caregivers don’t see eye-to-eye on the treatment experience

The above factors are most apparent when asking patients and caregivers to rate their experience with healthcare providers like their provincial government or their private insurance. Patients gave higher ratings than caregivers across the board, praising access, affordability, and timeliness significantly more than caregivers, who report having more difficulty obtaining benefits. Caregivers also report having to travel out-of-province for treatment more than patients did – although this may be due to the caregiver sample capturing more difficult (or terminal) cases.

The most striking finding with relation to the patient/caregiver disparity is who they consider to be most helpful when it comes to patient decision-making. Two thirds of caregivers say they are the ones helping their dependent make care choices, yet 86% of patients say it is their doctor or oncologist who is most influential. There is clearly a gap in communication between patients and caregivers, or a misunderstanding of who is ultimately making treatment decisions.
Caregivers struggle with mental health issues, but are not interested in informal support groups

Caregivers are also more likely to have difficulty finding flexible employment options, and emotional or psychological support. Many caregivers noted that it is not just their lifestyle, finances, or outlook that is affected by cancer – they struggle with mental health issues, too. While caregivers emphasize how important their role is, and how grateful it has made them for life and health, they also describe it as “emotionally draining”, “depressing”, and “stressful”. Patients are, understandably, more likely to focus on the physical changes to their quality of life.

What patients and caregivers do agree on is the importance of assistance programs, either within the formal healthcare structure (i.e. at hospitals and cancer clinics) or outside of it (through volunteer or advocacy organizations). Many respondents called out specific hospitals for excellent care and support, and a significant number identified the Canadian Cancer Society and the Volunteer Order of Nurses as being essential to their care and recovery.

However, few patients or caregivers have sought out patient/caregiver support groups. Fifty-five percent of patients are not interested in them, and only 20% report ever having attended such a group. Caregivers are less likely to be wholly uninterested but, again, only 19% have ever attended one. Those who are not interested say it is because they have enough support from family and friends or are fine on their own.
Patients and caregivers are wary about paying out-of-pocket

There is some interest in alternative health products and services, especially among caregivers. Both patients and caregivers seem willing to pay for services if they see them as supplementary – their treatment needs are being met through public healthcare, and they are seeking out options that complement, rather than replace, their current care. The example of a service that connects you to an oncology nurse over the phone received substantial interest – but little willingness to pay. Many oncologists, hospitals, and clinics already offer a similar service free-of-charge; if patients view telephone consultation as part of their core treatment, they are less willing to pay for it.

However, both patients and caregivers are open to the idea of a private business that offers supplemental services designed to enhance traditional healthcare – 52% of patients and 71% of caregivers are likely to utilize such a business. These services – be they alternative medicine, emotional counselling, or nutrition and exercise advice – appear to be needed add-ons not provided by the provincial system or covered by private insurance, and are therefore worth spending money on.
Pharmaceutical companies are not connecting with patients or caregivers

Both awareness of, and trust in, pharmaceutical companies among patients and caregivers is low, with less than half of the sample considering them to be a credible source of information and even fewer having taken advantage of their supplementary cancer services. As for Sanofi specifically, it has only 8% name recognition among patients, and 21% among caregivers.
Respondents differ on when government is allowed to stop treatment

Approximately half of patients (and 45% of caregivers) believe that it is never acceptable for the government to not provide treatment that could prolong a life, although three in ten say it is understandable if the patient is terminal.

Both patients and caregivers have unanswered – and unanswerable – questions

While both patients and caregivers feel that the majority of their queries are being answered by their medical or support teams, they are still full of unanswered – and unanswerable – questions. What caused my (or my loved one’s) cancer? Will it spread, or return? Is the worst over? Why is there no cure? Fundamentally, respondents are searching for explanations that may not exist and assurances that cannot be made.
DETAILED ANALYSIS OF RESULTS
PATIENTS
CANCER DIAGNOSIS

Within the sample of cancer patients, **28% currently have cancer and 72% have had the disease in the past**. The most common types of cancer diagnosed include prostate (23%), breast (17%), and colon/colorectal (11%), and over half of the respondents were diagnosed between 2000 and 2009.

**What type of cancer were you diagnosed with?**

- Prostate: 23%
- Breast: 17%
- Colon/colorectal: 11%
- Skin: 9%
- Ovarian: 5%
- Lung: 5%
- Uterine: 4%
- Thyroid: 4%
- Kidney: 3%
- Cervical: 3%
- Throat: 2%
- Testicular: 2%

**In what year were you first diagnosed with cancer?**

- Before 2000: 14%
- 2000-2009: 54%
- 2010-2013: 29%

Q4. Have you ever been diagnosed with cancer? Q6. What type of cancer were you diagnosed with? Q7. In what year were you first diagnosed with cancer? 

Base: Canadians who have or had cancer (n=301).
TREATMENT EXPERIENCE

Most patients were treated with surgery (69%), followed by radiation (40%) and chemotherapy (37%). Three quarters did not find it difficult to access the most current/effective treatment options, nor did they have difficulty accessing the medication they needed.

How was your cancer treated?

- Surgery, 69%
- Radiation, 40%
- Chemotherapy, 37%
- Other, 15%
- No treatment, 2%

How difficult was it for you to access the medication you needed?

- Not at all difficult: 51%
- Not very difficult: 26%
- Somewhat difficult: 10%
- Very difficult: 5%

Q8. How was your cancer treated? Q13H-I. Based on your experience, how difficult was it for you to...? Access the most current/effective treatment options that improve the overall quality of life for patients undergoing treatment for cancer; Access the medication you needed. Base: Canadians who have or had cancer (n=301).
The vast majority of patients (96%) report not having to travel outside their province to receive cancer treatment. Those who did travel largely stayed within Canada, travelling primarily because of a lack of availability of treatment.

**Q9. Did you have to travel outside of your province to receive cancer treatment?** Base: Canadians who have or had cancer (n=301).

<table>
<thead>
<tr>
<th>Province</th>
<th>Travelled</th>
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<tbody>
<tr>
<td>BC</td>
<td>2</td>
</tr>
<tr>
<td>AB</td>
<td>2</td>
</tr>
<tr>
<td>ON</td>
<td>1</td>
</tr>
<tr>
<td>NB</td>
<td>1</td>
</tr>
<tr>
<td>QC</td>
<td>1</td>
</tr>
<tr>
<td>Elsewhere within Canada</td>
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</tr>
<tr>
<td>US</td>
<td>2</td>
</tr>
<tr>
<td>International</td>
<td>1</td>
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</tbody>
</table>

**Q10A-B Where did you have to travel to? Why?** Base: Canadians who have or had cancer and travelled for treatment (n=13); NB. Small base size.

<table>
<thead>
<tr>
<th>Destination</th>
<th>Travelled</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elsewhere within Canada</td>
<td>3</td>
</tr>
<tr>
<td>US</td>
<td>2</td>
</tr>
<tr>
<td>International</td>
<td>1</td>
</tr>
</tbody>
</table>

**Why did you travel?**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waiting time was too long</td>
<td>15%</td>
</tr>
<tr>
<td>Availability of treatment</td>
<td>62%</td>
</tr>
<tr>
<td>Other</td>
<td>23%</td>
</tr>
</tbody>
</table>
Most patients acknowledge that cancer has impacted their quality of life, whether positively or negatively.

Q23. How has cancer impacted your quality of life? Base: Canadians who have or had cancer (n=301).

- “Life is on hold”
- “The biggest impact is the worry, rational or not.”
- “The will cancer would have been easier to deal with had I been able to afford the treatments I needed.”
- “No, I don’t even have an awareness [the] disease is even present. I am as active as ever, physically fit and eat healthy!”
- “I’ll never be the same, mentally.”
- “I felt cancer would have been easier to deal with had I been able to afford the treatments I needed.”
- “I never work, so am poorer, but appreciate every bit of life and no longer put things off.”
- “I was left with some permanent deficits from treatment. I would have preferred not, but cannot help but rejoice I am alive to face these challenges.”
- “I felt cancer would have been easier to deal with had I been able to afford the treatments I needed.”
- “I felt cancer would have been easier to deal with had I been able to afford the treatments I needed.”
- “I never work, so am poorer, but appreciate every bit of life and no longer put things off.”
- “I was left with some permanent deficits from treatment. I would have preferred not, but cannot help but rejoice I am alive to face these challenges.”
- “No, I don’t even have an awareness [the] disease is even present. I am as active as ever, physically fit and eat healthy!”
Half of Canadian cancer patients say they had few difficulties finding flexible employment options while undergoing treatment — only half report having little or no difficulty. Those who have access to private drug coverage are more likely to feel that way (57% vs. 37% with no access), potentially because they are salaried employees with flexible office careers. Residents of British Columbia are the least likely to say they had little to no difficulty finding employment (27% vs. 51% ROC).

Q13E. Based on your experience, how difficult was it for you to…? Find flexible employment options while being treated for cancer

<table>
<thead>
<tr>
<th>How difficult was it for you to find flexible employment options while being treated for cancer?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not difficult</td>
</tr>
<tr>
<td>- With private drug coverage: 49%</td>
</tr>
<tr>
<td>- Without private drug coverage: 37%</td>
</tr>
<tr>
<td>Difficult</td>
</tr>
<tr>
<td>- With private drug coverage: 18%</td>
</tr>
<tr>
<td>- Without private drug coverage: 26%</td>
</tr>
</tbody>
</table>

Base: Canadians who have or had cancer (n=301).
Patients say their doctors helped the most in making care-related decisions.

The majority of Canadian cancer patients say it was their physician who helped the most in making decisions related to their treatment, care and support.

Who has helped you the most in making the decisions you have had to make with respect to your treatment, care and support?

Net: 86%

- Doctor: 67%
- Oncologist: 50%
- Spouse: 44%
- Friends: 19%
- Kids: 16%
- Online information: 12%
- Parents: 11%
- Nurse: 11%
- Other healthcare professional: 6%

Q11. Who has helped you the most in making the decisions you have had to make with respect to your treatment, care and support? Base: Canadians who have or had cancer (n=301).
Overall, patients are pleased with the level of care they received from their provincial governments. Three quarters rate access to treatments highly, as do a similar share when asked about affordability. Timely access was slightly less praised, with 65% of patients rating it as excellent or very good.

Patients are largely satisfied with their provincial government’s coverage of cancer treatment.
Most patients do not have difficulty finding adequate medical facilities close to their home.

Eighty percent of Canadian cancer patients had few difficulties finding healthcare facilities with adequate medical equipment close to their residence.

Q13D. Based on your experience, how difficult was it for you to...? Find healthcare facilities with adequate medical equipment close to your residence. Base: Canadians who have or had cancer (n=301).

How difficult was it for you to find healthcare facilities with adequate medical equipment close to your residence?

- Not at all difficult: 60%
- Not very difficult: 20%
- Somewhat difficult: 12%
- Very difficult: 6%

Net: 80%
Patients find government health coverage accessible.

Two thirds of patients say it was not difficult for them to obtain adequate provincial benefits and insurance to cover the cost of their care. Even more feel it was not difficult to access the most current/effective treatment options available through public health coverage.

Q13G. Based on your experience, how difficult was it for you to...? Obtain adequate provincial benefits and insurance to cover the treatment costs. Q13J. Access the most current treatment/effective treatment options available through public health insurance. Base: Canadians who have or had cancer (n=301).
Half of patients believe it is never acceptable for the government not to provide treatment that could prolong a life. Women are more likely to feel this way than men (56% vs. 41% men), while older patients are more likely to believe it acceptable if the cancer is terminal (40% of 65+ vs. 17% of 18-54).

Q38. When is it understandable for the government not to provide treatments that can prolong a cancer patient’s life by only a few weeks with a good quality of life? Base: Canadians who have or had cancer (n=301).
PRIVATE COVERAGE OPTIONS

Only a third say they made use of private drug coverage

Half of patients say it was not difficult to obtain adequate private benefits and insurance to cover the costs of their care, and over a third report using private drug coverage for their treatment. A similar share has no access to private coverage for cancer medication.

How difficult was it for you to obtain adequate private benefits and insurance to cover treatment costs?

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all difficult</td>
<td>40%</td>
</tr>
<tr>
<td>Not very difficult</td>
<td>14%</td>
</tr>
<tr>
<td>Somewhat difficult</td>
<td>9%</td>
</tr>
<tr>
<td>Very difficult</td>
<td>12%</td>
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</tbody>
</table>

Net: 54%

Have you accessed private drug coverage for your cancer treatment?

<table>
<thead>
<tr>
<th>Access</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>36%</td>
</tr>
<tr>
<td>No, but I do have access to it if needed</td>
<td>27%</td>
</tr>
<tr>
<td>No, I do not have access to private drug coverage</td>
<td>34%</td>
</tr>
</tbody>
</table>

Q13F. Based on your experience, how difficult was it for you to obtain private benefits and insurance to cover the costs? Q14. Have you accessed private drug coverage for your cancer treatment? Base: Canadians who have or had cancer (n=301).
Sources of Support

Sixty-eight percent of Canadian cancer patients report little to no difficulty in obtaining adequate emotional/psychological support. Many also report positive experiences with patient assistance programs, with hospitals and cancer centres cited as the most common sources of support, followed by volunteer organizations like the Canadian Cancer Society and the Volunteer Order of Nurses.

Net: 68%

- Not at all difficult: 35%
- Not very difficult: 33%
- Somewhat difficult: 15%
- Very difficult: 7%

Q13B. Based on your experience, how difficult was it for you to…? Obtain adequate emotional/psychological support.

Q22. Please describe your experience with any patient assistance/support programs (financial, psychological, logistics support, infusion/injection clinics). Base: Canadians who have or had cancer (n=301).
Sources of Support, Continued

Most patients have not sought out patient support groups. Many patients do not seek out patient support groups. Fifty-five percent are not interested in them, and only 20% report ever having attended such a group. Those who did seek out a group were commonly encouraged by a healthcare professional, while those who have not sought one out feel they have enough support from family and friends.

Have you ever sought out or attended any patient support groups?

- **Have attended**: 20%
- **Have sought out but not attended**: 5%
- **Not sought out, but interested**: 18%
- **Not interested**: 55%

**Why?**
- Referenced by HCP (51%)
- Credibility of group (43%)
- Perceived benefit and compatibility (40%)
- Availability of supporting resources (36%)
- Recommendation from family and friends (21%)

**Why not?**
- I have enough support from family and friends (53%)
- I’m fine on my own (27%)
- I don’t think they work (6%)
- There are none available nearby (2%)

Q34. Have you ever sought out or attended any patient support groups? Base: Canadians who have or had cancer (n=301). Q35. Why/what encouraged you (or would encourage you) to seek out a patient support group? Base: Canadians with cancer who are open to patient support groups (n=76). Q36. Why are you not interested in patient support groups? Base: Canadians with cancer who are not interested in patient support groups (n=219).
Eighty-eight percent of patients do not find it difficult to access education or information on cancer prevention/treatment. Understandably, most began looking for information after they were diagnosed but before they began treatment.

Q13A. Based on your experience, how difficult was it for you to…? Access education on cancer prevention/treatment. Q24. At what moment did you begin looking for information about your condition? Base: Canadians who have or had cancer (n=301).
The **internet** (57%), their **oncologist** (53%), and their **family doctor** (53%) **are the most common sources patients reference** when seeking information about their condition. Patients are understandably most interested in treatment options (77%) and side effects (71%), but more than half are curious about the cause of their disease (59%).

Who/where have you gone for information?

- **Internet**: 57%
- **Oncologist**: 53%
- **Family doctor**: 53%
- **Doctor**: 45%
- **Surgeon**: 41%
- **Printed materials**: 38%
- **Nurse**: 19%
- **Radiologist**: 11%
- **Pharmacist**: 8%
- **Television**: 6%
- **Naturopath**: 5%
- **Dietician**: 5%
- **Family/friends**: 4%
- **Nutritionist**: 3%
- **Support group**: 1%
- **Other**: 3%

What information have you sought out?

- **Treatment options**: 77%
- **Treatment side effects**: 71%
- **Causes of the disease**: 59%
- **Emotional/psychological support**: 23%
- **Financial support**: 11%
- **Prognosis**: 2%
- **Other**: 5%
- **None**: 2%
Canadian cancer patients find oncologists and doctors (96% each) the most credible sources of information, followed by pharmacists and nurses. While many patients look to the internet for information on their disease, and 73% believe it to be a credible source, 39% are unsure of how to determine if a website is reliable.

How credible do you find each of the following sources to be?

- Doctor: 96%
- Oncologist: 96%
- Pharmacist: 89%
- Nurse: 88%
- Printed materials: 81%
- Internet: 73%
- Nutritionist: 72%
- Television: 47%
- Pharmaceutical companies: 40%
- Naturopath: 36%
- Printed materials: 81%
- Internet: 73%
- Nutritionist: 72%
- Television: 47%
- Pharmaceutical companies: 40%
- Naturopath: 36%

How do you determine if a website is reliable?

- It's from a professional organization: 22%
- Checking multiple sources: 11%
- Sources cited: 9%
- Reviews/popularity: 5%
- Ask my doctor: 4%
- If it sounds reasonable: 3%
- Just look for general information: 3%
- Other: 5%
- Don't know: 39%
Patients prefer to educate themselves on hospital, government, or cancer organization sites such as the Canadian Cancer Society and the Mayo Clinic. The reason why so many patients turn to the internet is that they are often looking for quick access to information (73%), or because it offers a variety of sources (60%).

Are there specific websites that stand out in your mind as having been particularly useful and reliable?

Canadian Cancer Society (9%)
WebMD Passport Santé (4%)
General government sites
Prostate Cancer Canada
Health Canada
BC Cancer Agency
Breastcancer.org (2%)

For what reasons do you consult the internet?

- 73% Quick access to information
- 60% Variety of information sources
- 39% Internet is neutral ground
- 28% To see where other patients get their info
- 10% Bad experience with HCP

Q31. Are there any specific websites that stand out in your mind as having been particularly useful and reliable (i.e. you trust the information they provide)?
Q32. For what reasons do you consult the internet and not a healthcare professional? Base: Canadians who have or had cancer (n=301).
Two in five patients look for alternative health information.

Forty-one percent of patients look for information on lifestyle changes or alternative health options to complement their treatment, primarily regarding dietary changes (73%) or changes in physical activity (57%).

Q27. Have you looked for any information on lifestyle changes/alternative health products or services to complement your treatment? Base: Canadians who have or had cancer (n=301).


- Dietary changes: 73%
- Changes in physical activity: 57%
- Overall lifestyle changes: 44%
- Alternative health products: 42%
- Alternative health services: 35%
- Use of vitamins: 2%
- Other: 5%
patients are generally in favor of out-of-hospital care, and 80% say they are likely to use a service that allows them to have treatment at home. However, 61% believe a patient should never have to pay out of pocket for products or services.

Q15. In your opinion, when, if at all, does it make sense for a patient to pay for health care out of pocket? Q16. Are you in favor or opposed to out of hospital care (clinics, home care, private centers)? Q17. If you had the option of receiving treatments at home, how likely would you be to use this service? Base: Canadians who have or had cancer (n=301).
Patients have mixed feelings on supplemental private health services

While 74% of patients say they are likely to use a service that linked them to oncology nurses over the phone, an equal number are not willing to pay for it. They are more open, however, to the idea of a private business that offers supplemental services designed to enhance traditional healthcare – 52% are likely to utilize such a business.

Q18. If you had access to speak to experienced oncology nurses on the phone, through a private service to answer questions, get second opinions and offer counseling etc, how likely would you be to use this service? Q19. How willing would you be to pay for this service? Q20. If a private business was offering wellness services designed to enhance and not replace traditional healthcare, such as nutrition and exercise counseling, natural health supplements recommendations, emotional counseling, etc, how likely would you be to use these services? Base: Canadians who have or had cancer (n=301).

74% likely to use service 20% willing to pay for service
FAMILIARITY WITH PHARMACEUTICAL COMPANIES

Awareness of pharmaceutical companies overall is fairly low, with over-the-counter giant Bayer the most recognized name at 65%. Sanofi has only 8% recognition among cancer patients, leading to a reputation score of 3%.

Do you have a good opinion, bad opinion, or you don't know the following companies?

<table>
<thead>
<tr>
<th>Company</th>
<th>Awareness</th>
<th>Reputation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bayer</td>
<td>65%</td>
<td>55%</td>
</tr>
<tr>
<td>Pfizer</td>
<td>51%</td>
<td>37%</td>
</tr>
<tr>
<td>BMS</td>
<td>38%</td>
<td>29%</td>
</tr>
<tr>
<td>Merck</td>
<td>37%</td>
<td>22%</td>
</tr>
<tr>
<td>GSK</td>
<td>32%</td>
<td>21%</td>
</tr>
<tr>
<td>Eli Lilly</td>
<td>24%</td>
<td>17%</td>
</tr>
<tr>
<td>Hoffman-La Roche</td>
<td>20%</td>
<td>12%</td>
</tr>
<tr>
<td>Novartis</td>
<td>19%</td>
<td>11%</td>
</tr>
<tr>
<td>Sanofi</td>
<td>8%</td>
<td>3%</td>
</tr>
<tr>
<td>Novo Nordisk</td>
<td>8%</td>
<td>4%</td>
</tr>
<tr>
<td>Janssen</td>
<td>6%</td>
<td>4%</td>
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Q37. Do you have a good opinion, bad opinion, or you don't know the following companies? Base: Canadians who have or had cancer (n=301).
USE OF SERVICES PROVIDED BY PHARMACEUTICAL COMPANIES

Few patients are aware of supplemental services offered by pharmaceutical companies, with only 12% having ever received these services. This is potentially due to a lack of trust; only 40% of patients believe pharmaceutical companies to be a credible source of information.

Three quarters of patients are unaware of supplementary services offered by pharmaceutical companies.
Most patients say they do not have unanswered questions, or have questions that cannot be answered.

Some are interested in alternative treatment recommendations, causes of their cancer, or unexpected side effects of treatment.

Q33. What types of unanswered questions do you have? Base: Canadians who have or had cancer? (n=301).
CAREGIVER SAMPLE

Sixty-two percent of the sample is currently the caregiver for someone with cancer, and 38% are former caregivers. Surprisingly, men are more likely to be current caregivers than women (71% vs. 57%).

QA5. Are you a caregiver for someone who has cancer? Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
CANCER DIAGNOSIS

The individuals with cancer for whom caregivers are responsible have been most commonly diagnosed with breast cancer (24%), lung cancer (16%), and colon/colorectal cancer (10%). Half of caregivers say this diagnosis occurred between 2010 and 2013.

What type of cancer were they diagnosed with?

- Breast: 24%
- Lung: 16%
- Colon/colorectal: 10%
- Brain: 8%
- Prostate: 7%
- Ovarian: 5%
- Gastric (stomach): 5%
- CLL: 4%
- Head and neck: 3%

In what year were they first diagnosed with cancer?

- Before 2000: 9%
- 2000-2009: 33%
- 2010-2013: 49%

QA6. What type of cancer were they diagnosed with? QA7. In what year were they first diagnosed with cancer? Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
TREATMENT EXPERIENCE

The most common treatment reported by caregivers is chemotherapy (58%), followed by surgery (48%) and radiation (47%).

Two thirds do not find it difficult to help their dependent access medication, and 79% have little trouble accessing the most current or effective treatments.

How was their cancer treated?

- Chemotherapy: 58%
- Surgery: 48%
- Radiation: 58%
- Other: 8%
- No treatment: 9%

How difficult was it for them to access the medication they needed?

- Very difficult: 4%
- Somewhat difficult: 15%
- Not very difficult: 34%
- Not at all difficult: 45%

Net: 79%

How difficult was it for them to access the most current/effective treatments?

- Not at all difficult: 28%
- Not very difficult: 38%
- Somewhat difficult: 23%
- Very difficult: 6%

Net: 66%
More caregivers report having to travel out of province for treatment than patients (15% vs. 4% patients). An equal share of those who travelled went to Ontario and the United States (23% each). Sixteen percent report a non-US international visit in order to seek treatment. Half of caregivers who travelled cite wait times as the reason, followed by availability of treatment (38%).

**Did you have to travel outside of your province to receive cancer treatment?**

- Yes, 15%
- No, 85%

**Where did you have to travel to?**
- ON: 7
- BC: 3
- AB: 3
- NB: 2
- QC: 2
- US: 7
- International: 5

**Why did you travel?**
- Waiting time was too long: 48%
- Availability of treatment: 38%
- New therapy: 7%
- Other: 7%
Most caregivers acknowledge that cancer has had a substantial impact on their life, from decreasing the quality of their mental health, to disrupting their own lives, to making them appreciate what they have.

Caregiving is “emotionally and physically draining.”

“I have increased concern for my health.”

“I had to make some major lifestyle changes in order to support the person I was taking care of.”

“Death is a part of life. Taking care of my dad while he was dying was what I wanted to do so, no, it did not impact the quality of my life. What it did do was change my priorities for a time.”

“Every last waking minute is spent finding information on new treatments and worrying. Every last dime has been spent to make sure our son has a good life.”

“Made me more aware of my own mortality.”

“It’s made some things tougher, but all in all I still keep a positive outlook on life.”

“It is harder to support myself financially.”

QA23. How has cancer impacted your quality of life? Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
Half of caregivers have difficulty finding flexible employment options while being a caregiver. Many note that it has forced them to choose between work and care, including taking time off from work or preventing them from moving for work. In addition, caregiving is a source of financial stress.

How difficult was it for you to find flexible employment options while being a caregiver?

- Very difficult: 18%
- Somewhat difficult: 31%
- Not very difficult: 20%
- Not at all difficult: 18%

Net: 49%
In stark contrast to the patient sample, two thirds of caregivers say they are the ones who help their dependents make decisions related to care. While 86% of patients say it is their doctor or oncologist who helps the most, only 67% of caregivers feel the same way.

Who has helped the most in making the decisions they have had to make with respect to their treatment, care and support?
SATISFACTION WITH PROVINCIAL GOVERNMENT

Though caregivers are generally satisfied with the access to and affordability of care provided by their provincial governments, they are less enthusiastic than patients. Only half of caregivers rate the timeliness of access to treatments highly.

- **Access to cancer treatment**: 62%
- **Affordable access to cancer treatment**: 63%
- **Timely access to treatment**: 55%

QA12. Based on your experience, how would you rate the provincial government’s ability to provide each of the following? Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
Seventy percent of caregivers do not have difficulty finding healthcare facilities with adequate medical equipment close their residence.

How difficult was it for you to find healthcare facilities with adequate medical equipment close to your dependent's residence?

- Not at all difficult: 36%
- Not very difficult: 34%
- Somewhat difficult: 19%
- Very difficult: 10%

Net: 70%

Q13D. Based on your experience, how difficult was it for you to...? Find healthcare facilities with adequate medical equipment close to your residence. Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
GOVERNMENT COVERAGE

Caregivers are more split than patients on whether or not it is difficult to obtain adequate provincial benefits and insurance to cover their costs. Forty-eight percent characterize the experience as not difficult, while 38% find it difficult. Those who are open to supplemental treatment supplied by a private business are more likely to find obtaining provincial coverage difficult (44% vs. 22% not likely to use).

Two thirds of caregivers do not find it difficult to help their dependents access the most current/effective treatment options available through public health coverage; however, those likely to use private services are more likely to find it difficult (37% vs. 15% not likely).

How difficult was it for you to obtain adequate provincial benefits and insurance to cover treatment costs?

- Not at all difficult: 25%
- Not very difficult: 23%
- Somewhat difficult: 24%
- Very difficult: 14%

Net: 48%

How difficult was it for you to access the most current/effective treatment options available through public health coverage?

- Not at all difficult: 31%
- Not very difficult: 35%
- Somewhat difficult: 24%
- Very difficult: 7%

Net: 66%
Government Coverage Responsibility

Forty-five percent of caregivers believe that it is never understandable for the government to not provide life-prolonging treatment to a cancer patient.

When is it understandable for the government not to provide treatments that can prolong a cancer patient’s life by only a few weeks with a good quality of life?

- If the cancer is terminal: 29%
- If the cost is too high: 17%
- If the patient doesn’t want it: 2%
- This is never understandable: 45%

Three in ten caregivers believe it is understandable for the government not to provide treatments when a patient’s cancer is terminal.
PRIVATE COVERAGE OPTIONS

Caregivers faced difficulty acquiring private coverage for their dependents.

Caregivers report having a harder time acquiring adequate private benefits and insurance than patients; while 42% have little to no difficulties, 37% had trouble obtaining coverage for their dependent.

Two in five caregivers say their dependents made use of private drug coverage for their treatment, while 35% report having no access at all.

How difficult was it for you to obtain adequate private benefits and insurance to cover treatment costs?

- Not at all difficult: 18%
- Not very difficult: 24%
- Somewhat difficult: 26%
- Very difficult: 11%

Net: 42%

Have you accessed private drug coverage for your cancer treatment?

- Yes: 42%
- No, but I do have access to it if needed: 15%
- No, I do not have access to private drug coverage: 35%

QA13F. Based on your experience, how difficult was it for you to...? Obtain private benefits and insurance to cover the costs. QA14. Have they accessed private drug coverage for their cancer treatment? Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
SOURCES OF SUPPORT

Half of caregivers do not find it difficult to obtain adequate emotional or psychological support. They report mixed experiences with health and home care medical teams, but are largely appreciative of any support that is offered.

<table>
<thead>
<tr>
<th>How difficult was it for you to obtain adequate emotional/psychological support?</th>
<th>Not at all difficult</th>
<th>Not very difficult</th>
<th>Somewhat difficult</th>
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<td></td>
<td>22%</td>
<td>30%</td>
<td>32%</td>
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</table>

Net: 52%

“Money was tight. I had to leave school to support the house.”

“The patient is currently on a trial drug financed by the drug company.”

“We were helped by a hospital staff member whose entire role was to find funding for patients who did not have private health insurance.”

“I have found there is very little support provided for out-care patients, and where it does exist the waiting list is months to years long.”

“Good palliative care from the nurses, great co-operation from the hospital, and exceptional help from the VON.”

“My employer's extended medical care program was of great help.”

QA13B. Based on your experience, how difficult was it for you to...? Obtain adequate emotional/psychological support. QA22. Please describe your experience with any patient assistance/support programs (financial, psychological, logistics support, infusion/injection clinics). Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
Sources of Support, Continued

Like patients, many caregivers are not interested in a support group (39%), and only 19% have ever attended one. The likelihood of caregivers taking advantage of such groups depends on their local availability, and on a recommendation from a healthcare professional. Those who are not interested say it is because they have enough support from family and friends (47%), or are fine on their own (20%).

Have you ever sought out or attended any patient/caregiver support groups?

<table>
<thead>
<tr>
<th></th>
<th>Have attended</th>
<th>Have sought out but not attended</th>
<th>Not sought out, but interested</th>
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<tr>
<td>Have attended</td>
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Why?
- Availability of supporting resources (52%)
- Referenced by HCP (51%)
- Recommendation from family and friends (28%)
- Perceived benefit and compatibility (24%)
- Credibility of group (17%)

Why not?
- I have enough support from family and friends (47%)
- I’m fine on my own (20%)
- I don’t think they work (12%)
- There are none available nearby (3%)
Three quarters of caregivers do not find it difficult to access education on cancer prevention/treatment. Two thirds began looking for information about their dependent’s condition after their diagnosis but before treatment began.

When did you begin looking for information about your dependent’s condition?

- Prior to diagnosis, 18%
- After diagnosis, before treatment, 68%
- After treatment, 7%
- Other, 1%
- I never looked for info, 6%

How difficult was it for you to access education on cancer prevention/treatment?

- Not at all difficult: 37%
- Not very difficult: 40%
- Somewhat difficult: 14%
- Very difficult: 6%

Net: 77%
 Most caregivers go to a doctor (63%) or the internet (59%) when looking for information, where they seek out treatment options (81%), followed by side effects (72%) and causes of the disease (63%).

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<thead>
<tr>
<th>Who/where have you gone for information?</th>
<th>63%</th>
<th>59%</th>
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Caregivers are more likely than patients to find pharmaceutical companies credible.

Caregivers find doctors to be the most credible source of information (95%), followed by nurses and oncologists (91% each), and pharmacists (88%). While 71% believe the internet to be a credible source of information, 45% of caregivers do not know how to determine if a website is reliable.

How credible do you find each of the following sources to be?

- Doctor: 95%
- Oncologist: 91%
- Nurse: 91%
- Pharmacist: 88%
- Printed materials: 85%
- Nutritionist: 78%
- Internet: 71%
- Pharmaceutical companies: 55%
- Television: 51%
- Naturopath: 48%
- Printed materials: 85%
- Nutritionist: 78%
- Internet: 71%
- Pharmaceutical companies: 55%
- Television: 51%
- Naturopath: 48%
- It's from a professional organization: 17%
- Sources cited: 10%
- Checking multiple sources: 8%
- Ask my doctor: 5%
- Reviews/popularity: 4%
- Just look for general information: 2%
- If it sounds reasonable: 1%
- Other: 6%
- Don’t know: 45%
INTERNET AS SOURCE

Like patients, caregivers choose to visit the sites of government, hospital, or cancer groups – such as the Canadian Cancer Society, the Mayo Clinic, or Health Canada. They prefer to consult the internet when they need quick access to information, or want to see a variety of sources.

Are there specific websites that stand out in your mind as having been particularly useful and reliable?

For what reasons do you consult the internet?

- Quick access to information: 71%
- Variety of information sources: 55%
- To see where other patients get their info: 30%
- Internet is neutral ground: 28%
- Bad experience with HCP: 6%
Approximately half of caregivers have looked for information on lifestyle changes or alternative health products to complement their dependents’ treatment, compared to only 41% of patients. Caregivers are looking for information on dietary changes (78%), changes in physical activity (53%), or overall lifestyle changes (42%).

QA27. Have you looked for information on lifestyle changes/alternative health products or services to complement the treatment? QA28. What type of information did you look for? Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
Three quarters of caregivers are in favour of out-of-hospital care for cancer patients, and 87% say their dependent would be likely to take advantage of the option of receiving treatment at home. However, 62% of caregivers believe a patient should never have to pay for services out-of-pocket – the same share as patients themselves.
Eighty-seven percent of caregivers say they are likely to take advantage of a service where they can connect with oncology nurses over the phone. When asked if they would pay for such a service, only 43% were willing to do so – however this is **significantly more than the number of patients willing to pay**. Caregivers are **also more open to a private business that offers supplemental services designed to enhance traditional healthcare** – 71% are likely to utilize such a business, compared to 52% of patients.

**If a private business was offering wellness services designed to enhance and not replace traditional healthcare, how likely would you be to use these services?**

- **Very likely**: 26%
- **Somewhat likely**: 44%
- **Not very likely**: 19%
- **Not at all likely**: 10%

Net: 71%

**QA18.** If you had access to speak to experienced oncology nurses on the phone, through a private service to answer questions, get second opinions and offer counseling etc, how likely would you be to use this service? **QA19.** How willing would you be to pay for this service? **QA20.** If a private business was offering wellness services designed to enhance and not replace traditional healthcare, such as nutrition and exercise counseling, natural health supplements recommendations, emotional counseling, etc, how likely would you be to use these services? Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
FAMILIARITY WITH PHARMACEUTICAL COMPANIES

Awareness of pharmaceutical companies is somewhat low among caregivers, with Bayer (63%) and Pfizer (51%) being the most recognized. **More caregivers are aware of Sanofi than patients** (21% vs. 8% patients), and give the company a significantly higher reputation score.

**Do you have a good opinion, bad opinion, or you don’t know the following companies?**

- Bayer: 63% Awareness, 47% Reputation
- Pfizer: 51% Awareness, 28% Reputation
- BMS: 42% Awareness, 26% Reputation
- Merck: 40% Awareness, 24% Reputation
- GSK: 35% Awareness, 20% Reputation
- Eli Lilly: 32% Awareness, 16% Reputation
- Novartis: 31% Awareness, 16% Reputation
- Hoffman-La Roche: 24% Awareness, 10% Reputation
- Novo Nordisk: 23% Awareness, 13% Reputation
- Janssen: 22% Awareness, 10% Reputation
- Sanofi: 21% Awareness, 9% Reputation

QA37. Do you have a good opinion, bad opinion, or you don’t know the following companies? Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
Caregivers are more likely to be aware of these services than patients are.

Fifty-five percent of caregivers find pharmaceutical companies to be credible sources of information. Yet only 22% of caregivers have taken advantage of supplemental services offered by pharmaceutical companies; 62% are unaware such services existed.

Have you ever received any of these free supplementary services?

- Yes, 22%
- No, but we are aware of them, 14%
- No, we are not aware of them, 62%
Most caregivers say they do not have unanswered questions, or have questions that cannot be answered.

Some are interested in alternative treatment recommendations, causes of cancer, or the chances of their dependent’s survival.

---

**QA33. What type of unanswered questions do you have?**
Base: Canadians who are or have been a caregiver for someone with cancer (n=201).
APPENDIX
GENDER

Patients: 50%

Caregivers: 37%

Caregivers: 63%

Patients: 50%
<table>
<thead>
<tr>
<th>AGE</th>
<th>18-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
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<tbody>
<tr>
<td>Patients</td>
<td>1%</td>
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<td>6%</td>
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<td>Caregivers</td>
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Regional Breakdown:

- **British Columbia**
  - Patients: 10%
  - Caregivers: 10%

- **Alberta**
  - Patients: 12%
  - Caregivers: 7%

- **Saskatchewan**
  - Patients: 2%
  - Caregivers: 3%

- **Manitoba**
  - Patients: 2%
  - Caregivers: 5%

- **Ontario**
  - Patients: 31%
  - Caregivers: 35%

- **Quebec**
  - Patients: 40%
  - Caregivers: 34%

- **Atlantic Canada**
  - Patients: 3%
  - Caregivers: 7%